

MARI LUNDBERG

Kinesiophobia

*Various Aspects of
Moving with Musculoskeletal Pain*

Kinesiophobia – Various Aspects of Moving with Musculoskeletal Pain

MARI LUNDBERG



Department of Orthopaedics, Institute of Clinical Sciences · The Sahlgrenska Academy at Göteborg University
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Intellecta Docusys

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To my grandmother Karin Glennvall (1902-1996)

“One of the things that keep my mood better is actually the exercise, because I keep doing it and when I leave here (the physiotherapy department) I feel better, both mentally and physically. When I leave, for instance, I can feel it’s easier to walk, that I’m less tense, so I know that exercise makes me feel better. It strengthens my whole self”.

One of the Patients with Musculoskeletal Pain in This Thesis

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LIST OF PAPERS

This thesis is based on the following studies, referred to in the text by their Roman numerals.

I. Lundberg MKE, Styf J, Carlsson SG. A psychometric evaluation of the Swedish version of the Tampa Scale for Kinesiophobia (TSK) – from a physiotherapeutic perspective. *Physiotherapy Theory and Practice* 2004; 20: 121-133.

II. Lundberg M, Jansson B, Styf J. The multidimensionality of the Swedish version of the Tampa Scale for Kinesiophobia. *Submitted for publication in European Journal of Pain, 2006.*

III. Lundberg M, Larsson M, Östlund H, Styf J. Kinesiophobia among patients with musculoskeletal pain in primary health care. *Journal of Rehabilitation Medicine* 2006; 1: 37-43.

IV. Lundberg M, Styf J, Bullington J. Moving with chronic pain – a qualitative study from a patient perspective. *Accepted for publication in Physiotherapy Theory and Practice, 2006.*

ABBREVIATIONS

BDI	Beck Depression Inventory
DRI	Disability Rating Index
DSM-IV	Diagnostic and Statistical Manual of the American Psychiatric Association, fourth edition
EFA	Exploratory Factor Analysis
EPP	Empirical Phenomenological Psychological
FABQ	Fear Avoidance Beliefs Questionnaire
FSS	Fear Survey Schedule
IASP	International Association for the Study of Pain
MPI	Multidimensional Pain Inventory
MPI-S	Multidimensional Pain Inventory- Swedish version
SEM	Standard Error of Measurement
STAI	Spielberger State and Trait Inventory
TSK	Tampa Scale for Kinesiophobia
TSK-SV	Tampa Scale for Kinesiophobia-Swedish Version
TSK-DV	Tampa Scale for Kinesiophobia- Dutch Version
VAS	Visual Analogue Scale

DEFINITIONS IN SHORT

Chronic pain	pain which persists beyond the normal time of healing (<i>IASP, 1994</i>) three months is the most convenient point of division between acute and chronic pain, but for research purposes six months will be preferred (<i>IASP, 1994</i>)
Concept	an abstraction based on observations of certain behaviours or characteristics (<i>Polit and Hungler, 1999</i>)
Construct	an abstraction or concept that is deliberately invented (constructed) by researchers for a scientific purpose (e.g. depression, fear, kinesiophobia) (<i>Polit and Hungler, 1999</i>)
Fear of movement	a specific fear of movement and physical activity that is (wrongfully) assumed to cause reinjury (<i>Vlaeyen et al., 1995</i>)
Informant	the person (or patient) who is being interviewed in a qualitative methodology, can also be called respondent or participant.
Kinesiophobia	an excessive, irrational, and debilitating fear of physical movement and activity resulting from a feeling of vulnerability to painful injury or reinjury (<i>Kori, Miller and Todd, 1990</i>)
Pain-related fear	incorporates fear of pain, fear of injury, fear of physical activity and so forth (<i>Asmundson et al., 1996</i>)
Persistent pain	pain present most of the time for a period of six months or more during the prior year (<i>Gureje, et al., 1998</i>)
Phenomenology	is both a philosophical movement and a research methodology. In this thesis it is referred to as a qualitative research methodology, that emphasizes how people understand the world and construct meaning out of their experiences

Physical activity	any bodily movement, produced by skeletal muscles, that result in energy expenditure (<i>Cider, 2005 Adapted from Casparsen, Powell and Christenson, 1985; Pate et al, 1995</i>)
Physical exercise	a subset of physical activity that is planned, structured, repetitive and purposeful in the sense that improvement or maintenance of physical fitness is the objective (<i>Cider, 2005 Adapted from Casparsen, Powell and Christenson, 1985; Pate et al, 1995</i>)
Physiotherapy	=Physical therapy
Psychometrics	the field of study concerned with the theory and technique of psychological measurement, which includes the measurement of knowledge, abilities, attitudes, and personality traits (<i>Nunnally and Bernstein 1994</i>).
Reliability	the degree of consistency or dependability with which an instrument measures the attribute to which it is designed to measure (<i>Polit and Hungler, 1999</i>)
Validity	the degree to which an instrument measures what it is intended to measure (<i>Polit and Hungler, 1999</i>)

ABSTRACT

Mari Lundberg, Kinesiophobia – various aspects of moving with musculoskeletal pain. Department of Orthopaedics, Institute of Clinical Sciences, the Sahlgrenska Academy at Göteborg University, Göteborg, Sweden.

The overall aim of this thesis was to investigate various aspects of the phenomenon of kinesiophobia among patients with musculoskeletal pain. In order to be able to assess kinesiophobia, a reliable and valid measure was needed. Study I evaluated the psychometric properties of the Swedish language version of the Tampa Scale for Kinesiophobia (TSK-SV) questionnaire. The reliability test included stability over time, internal consistency and homogeneity. The test of validity included face validity, content validity and construct validity. The TSK-SV was found to be reliable and evidence supported its validity, although the results indicated a lack of construct validity. An exploratory factor analysis in Study II was performed to explore the conceptual dimensions of the TSK-SV questionnaire based on a large Swedish sample. The findings showed that the TSK-SV measured five different dimensions of kinesiophobia. The aims of Study III were to describe the occurrence of kinesiophobia and to investigate the association between kinesiophobia and pain variables, physical activity measure and psychological characteristics in patients with musculoskeletal pain. A multiple logistic regression model was performed to identify associations. Kinesiophobia was a commonly seen phenomenon in patients with musculoskeletal pain. The results further indicated that kinesiophobia was associated with pain variables, physical activity measures and psychological characteristics. Study IV explored how patients with persistent musculoskeletal pain experienced *moving with pain*. The interviews were analyzed according to a qualitative method called the Empirical Phenomenological Psychological (EPP) method. The results were described in three typologies called *Failed adaptation*, *Identity restoration* and *Finding the way out*.

In conclusion, TSK-SV is a reliable and valid measure that can be used in order to assess to what extent the patient fears physical movement. It is, however, important to stress that TSK-SV not can be used as a single measure of diagnoses, but simply gives a rough indication of the level of pain-related fears. This thesis also shows that moving with pain has a deep existential impact on the individual, which needs to be taken into account when treating patients with persistent musculoskeletal pain.

Keywords: fear of movement, kinesiophobia, movement, persistent pain, phenomenology, physical therapy, psychometric properties, reliability, validity.

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SAMMANFATTNING PÅ SVENSKA- SUMMARY IN SWEDISH

Bakgrund

Smärta är en naturlig del av livet och nästan alla människor drabbas någon av smärta ifrån muskler och leder. Hur man påverkas av att ha ont är mycket individuellt, men att smärtan påverkar så väl tankar som känslor är väl känt. Vid akut smärta är det fullständigt normalt att man är rädd för att röra sig. Däremot kan det vara mycket negativt på lång sikt, både för kropp och själ, om man undviker att röra sig. Om en person har en ”överdriven, irrationell rädsla för fysisk aktivitet” kallas detta för *kinesiofobi*. Fenomenet benämns även *rörelserädsla* och har visat sig ha negativa effekter för den som har ont. Sjukgymnaster är den vårdgivare som oftast träffar patienter med smärta ifrån muskler och leder. Det är därför angeläget att denna yrkesgrupp har bra kunskap om kinesiofobi och olika faktorer som hindrar en framgångsrik rehabilitering.

Målsättning

Målsättningen med denna avhandling var att utifrån olika perspektiv beskriva och identifiera den rädsla för rörelse som riskerar att skapa negativa effekter hos patienter med smärta från muskler och leder.

Mätmetoder för kinesiofobi

För att kunna beskriva och identifiera hur vanligt kinesiofobi är hos patienter utvärderades på flera olika sätt tillförlitligheten (reliabilitet) och trovärdigheten (validitet) av den svenska versionen av frågeformuläret, *Tampaskalan för kinesiofobi (TSK-SV)*. TSK-SV visade sig ha god vetenskaplig kvalitet och kan därför användas för att identifiera kinesiofobi hos patienter med långvarig smärta.

Förekomst av kinesiofobi

TSK-SV visade att 70% av patienter med smärta från muskler och leder hade en hög grad av *kinesiofobi*. 1294 personer tillfrågades och 714 (55%) tackade ja till att delta.

Kinesiofobi i relation till andra faktorer

Det visade sig att *kinesiofobi* hade starkast samband med hur fysiskt aktiv patienten bedömde sig vara och hur intensiv patienten beskrev sin smärta

vara. Däremot fanns det inget samband med kinesiofobi och faktorerna: *om man tränade eller inte* samt *om man hade fastställt en diagnos eller inte*.

Patientens upplevelse av att röra sig med smärta

All forskning hitintills angående *kinesiofobi* har utgått ifrån forskarens perspektiv. I den fjärde delstudien av denna avhandling undersöktes hur patienter med långvarig smärta ifrån muskler och leder upplevde det att röra sig med smärta. Patienterna intervjuades med så kallade djupintervjuer, som analyserades med den kvalitativa metoden *Empirical Phenomenological Psychological (EPP)*. Patienterna fick på olika sätt i detalj beskriva hur det på olika sätt påverkade dem att röra sig med smärta. Resultaten av djupintervjuerna kunde delas in i tre grupper; *Misslyckad anpassning*, *Återuppbyggnad av identitet* och *Att hitta vägen ut*.

Slutsats

Sammanfattningsvis är TSK-SV ett tillförlitligt instrument att använda på svenska patienter med smärta från muskler och leder. TSK-SV kan användas för att bedöma en patients grad av *överdriven rädsla för rörelse*. Denna avhandling visar tydligt att röra sig med smärta har en djup existentiell påverkan på individen, vilket måste tas hänsyn till när man behandlar patienter med långvarig smärta från muskler och leder. Avhandlingens resultat pekar även tydligt på att fysisk aktivitet måste uppmuntras för att kunna förebygga att patienterna får en *irrationell och överdriven rädsla för rörelse*.

Framtiden

Metoder för uppmuntran av rörelse och fysisk aktivitet bör noga relateras till vilken mening varje enskild människa tillskriver att röra sig. Rörelse är liv och glädje och måste i större grad än tidigare integreras i all rehabilitering. Tidigare forskning har visat vikten inte bara ge allmänna råd om den positiva betydelsen av att röra sig. För bästa resultat bör aktiviteten dessutom prövas på och genomföras under ledning av en erfaren och kunnig sjukgymnast eller motsvarande. Budskapet måste dessutom vara tydligt enhetligt längs hela vårdkedjan. Utmaningen för vården ligger i att organisera ett system som minskar patienters rädsla för rörelse och uppmuntrar fysisk aktivitet.

INTRODUCTION

The Road Not Taken

*Two roads diverged in a yellow wood,
And sorry I could not travel both
And be one traveler, long I stood
And looked down one as far as I could
To where it bent in the undergrowth;*

*Then took the other, as just as fair
And having perhaps the better claim,
Because it was grassy and wanted wear;
Though as for that the passing there
Had worn them really about the same,*

*And both that morning equally lay
In leaves no step had trodden black,
Oh, I kept that first for another day!
Yet knowing how way leads on to way,
I doubted if I should ever come back,*

*I shall be telling this with a sigh
Somewhere ages and ages hence:
Two roads diverged in a yellow wood, and I-
I took the one less traveled by,
And that has made all the difference.*

(Robert Frost 1874-1963)

My starting point of departure in writing this thesis was an urge to understand the underlying aspects of pain that influence the rehabilitation process. Having worked with patients with pain as a physical therapist in various settings for almost a decade, it became evident to me that pain had a negative impact of more than the physiological level. It was also my clinical experience that physical exercise had a positive impact on the patient's rehabilitation outcome. However, there was a group of patients who seemed afraid of moving their body. Although they had passed the acute phase of

pain, they behaved as if they were stuck in that phase. It was more than just a lack of motivation. In my search for a deeper understanding of factors that influence the rehabilitation process, the phenomenon of kinesiophobia was introduced to me. Kinesiophobia was originally defined as a condition in which a patient has “*an excessive, irrational, and debilitating fear of physical movement and activity resulting from a feeling of vulnerability to painful injury or reinjury*”(Kori et al., 1990). As a physical therapist I was especially interested in the effects of the *debilitating fear of physical movement* on the patient. I started out from a bio-medical perspective, but my research questions guided me through unknown lands of psychology and philosophy. From the beginning I was not convinced about which road to take, but I took the one less travelled by, and that has made all the difference.

BACKGROUND

1. Persistent musculoskeletal pain

This dissertation deals with musculoskeletal pain. The concept of musculoskeletal pain, as used in this thesis, is not seen as a disease, but as a natural condition that most people experience at some point in life. Pain is the primary symptom that motivates people to seek medical treatment (Knapp and Koch, 1984, Gureje et al., 1998, Gerdle et al., 2004). Persistent pain derives predominantly from the musculoskeletal system (Andersson et al., 1993). Musculoskeletal disorders comprise over 200 different diagnoses, including various arthropathies, back problems, soft tissue disorders, bone conditions and trauma (Lee, 1994). In many cases of musculoskeletal pain it is difficult to establish specific diagnoses, and the causes of the complaints remain unknown. The basic belief underpinning this thesis is that pain can be apprehended and studied as a concept, without any need to pinpoint the actual cause.

1.1. Prevalence and incidence

The overall prevalence of musculoskeletal pain in the population varies considerably between studies, largely due to differences in methodology, but it is uniformly high (Cunningham and Kelsey, 1984, Lee et al., 1985, Lee, 1994, Bassols et al., 1999, Gerdle et al., 2004)

Back pain is the most commonly reported pain localisation. The population cumulative lifetime prevalence of low back pain has been reported in a review by McBeth and Macfarlane (2002) to be in the range of 50-84%. The prevalence of current symptoms (period and point prevalence) is generally lower, ranging from 18-59% (McBeth and Macfarlane, 2002).

Shoulder and neck pain are the second most commonly reported pain localisations (Croft et al., 1994). Owing to methodological problems in defining shoulder pain there are only sparse data describing the cumulative life time prevalence of shoulder pain in the general population (McBeth and Macfarlane, 2002). Given the most stringent definition (Jacobsson et al., 1989) 1 out of 20 people in a Swedish population had experienced shoulder pain in the last year. Badley and Tennant (1992) reported a rate of 6.9% in a UK population. It is clear that a considerable proportion of people in the community experience shoulder pain. The prevalence of neck pain ranges from 25 to 85% (Rekola et al., 1997, Guez, 2006).

There are no studies of the cumulative lifetime prevalence of persistent widespread pain and only a limited number of studies have specifically examined the period and point prevalence (Croft et al., 1993, Wolfe et al., 1995, Hunt et al., 1999, White et al., 1999, Lindell et al., 2000). Regardless of pain site there is a high prevalence of musculoskeletal pain in the population, causing activity limitation and long term disability (Biering-Sorensen, 1984, Mayer, 1987, Nachemson, 1991, Frymoyer, 1992, Lancourt and Kettelhut, 1992, Lindström et al., 1992, Nachemson and Jonsson, 2000).

The prevalence of persistent widespread pain is more frequently reported by women than by men (Bergman et al., 2001, Gerdle et al., 2004, Thomas et al., 2004), but there are contradictory results as well (Brattberg et al., 1989, Andersson et al., 1993).

1.2. Definitions and classifications

"Pain is an unpleasant and emotional experience associated with actual or potential tissue damage, or described in terms of such damage" (Merskey, 1979). The consensus definition of pain developed by the International Association for the Study of Pain (IASP) is an umbrella term for all kinds of pain, regardless of origin. Pathological or physiological evidence of tissue damage is not required for a diagnosis of pain. Pain is hence not a specific sensation, but a complex perceptual experience that involves sensory-discriminative, affective-motivational and cognitive-evaluative components (Melzack and Wall, 1965, Melzack and Casey, 1968). The sensory component involves perception of pain intensity, duration and localisation, the emotional component attributes emotional colouring to the pain experience, being responsible for the behavioural part of pain, and the cognitive component refers to our previous experiences, thoughts and ideas. These components can be found in all types of pain regardless of its origin. They interplay differently at various stages of the pain process and in different individuals. The sensory-discriminate component dominates the acute phase of pain, whereas the other two are more distinct in the persistent phase.

Although there are several ways of classifying pain, there is no one system universally accepted by clinicians or researchers (Turk and Melzack, 2001). Based on the pathological origin, pain can be classified into four groups: nociceptive pain, inflammatory pain, neuropathic pain and functional pain. Nociceptive pain is transient pain in response to a noxious stimulus. Inflammatory pain is spontaneous pain and hypersensitivity to pain in relation to tissue damage and inflammation. Neuropathic pain is spontaneous pain and hypersensitivity to pain in association with damage to or a lesion of the

nervous system. Functional pain is hypersensitivity to pain resulting from abnormal central processing of normal input (Woolf, 2004).

Chronic pain has been defined as "... *that which persists beyond the normal time of healing*" and three months is considered "... *the most convenient point of division between acute and chronic pain, but for research purposes six months will be preferred*" IASP (1994). The operational definition of chronic pain in this thesis is pain that has lasted for six months or more. Persistent pain is defined as pain that was present most of the time for a period of six months or more during the prior year (Gureje et al., 1998). Chronic and persistent pain are used interchangeably throughout this thesis, although I prefer the word persistent. Persistent pain is not merely acute pain that persists over time; changes occur at different levels of the pain transmission system (Sterner and Gerdle, 2004). Acute pain and persistent pain are thus not the same condition.

1.3. Pain theories and models

The nature of pain has puzzled humanity for centuries and various *pain models* have been presented. Plato (ca 427-347 BC) believed that pain arose not only from peripheral sensation but as an emotional response in the soul, which resided in the heart. Aristotle (384-322 BC) believed that the brain had no direct function in sensory processes and therefore played no part in the experience of pain.

1.3.1. The bio-medical model

The pain model of Descartes (1596-1650), often referred to as the Cartesian model or the *bio-medical model*, is the one on which our modern health care system was built. Descartes considered thinking an activity quite separate from the body, as emphasized in his famous statement "Cogito ergo sum (I think therefore I am)" (Discourse on the Method, 1637). A more elaborate quotation clarifies his statement:



“From that I knew I was a substance, the whole essence or nature of which is to think, and that for its existence there is no need of any place, nor does it depend on any material thing; so that is me, that is to say, the soul by which I am what I am, is entirely distinct from body, and is even more easy to know than is the latter; and even if body were not, the soul would not cease to be what it is” (Descartes, 1644)

Figure 1. Reflex action as envisaged by Descartes. While the figure shows that Descartes anticipated the basic idea of reflex action, it also indicates that he did not realize the anatomical distinction between sensory and motor nerves (From Descartes, 1662).

The distinct separation between body and mind made by Descartes has been called Descartes' error (Damasio, 1994). However, it must be borne in mind that Descartes was the first to hint that there could be nociceptors in the periphery and nociceptive pathways in the brain. Pain in the absence of physical pathology, physical pathology with no pain, and variable responses do not easily fit with a purely biomedical view of persistent pain. Moreover, the association between objectively established physical impairments and disability is rather weak (Waddell, 1987, Turk, 1999). Other factors must contribute to patients' reports of pain.

1.3.2. Gate control theory

The **gate control theory** was introduced in 1965 by psychologist Melzack and anatomist Wall (Melzack and Wall, 1965), and caused a revolution in the understanding of pain mechanisms. Gate control theory provided the first physiological mechanism for psychological interventions to minimise pain, such as distraction or relaxation, and shifted attention away from the peripheral source of injury and towards the spinal cord and brain. Small fibre activity tends to facilitate the passage of information up the spinal cord (“opening the gate”), whereas large fibre activity inhibits the flow of information (“closing the gate”). This is one reason that rubbing a region of soreness helps to reduce pain.

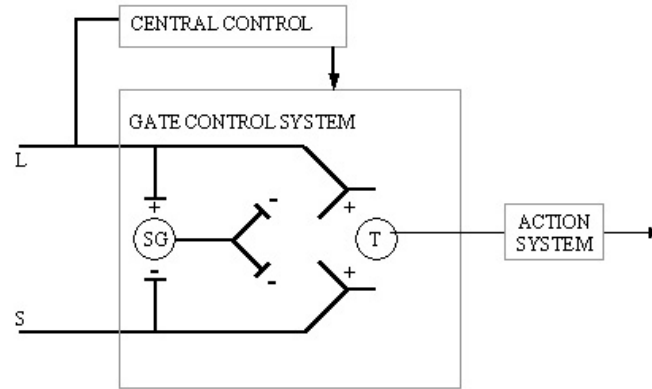


Figure 2. A schematic illustration of the gate control theory of pain. Transmission cells (T) in the spinal cord receive excitatory input (+) from large (l) and small (s) afferent fibres. The transmission cells receive inhibitory (-) inputs from spinal inhibitory cells localized in Substantia Gelatinosa (SG). The balance of large and small fibre input determines the output from the inhibitory cells. Transmission cells send output to the brain, which can return inhibitory or excitatory information. Reprinted with permission from Melzack et al. *SCIENCE* 150: 971-979. Copyright 1965 AAAS.

Although some of the neurophysiological details were later disproved (Franz and Iggo, 1968, Zimmermann, 1968, Nathan, 1976) the gate control provided a new perspective on pain. First, in terms of a significant contribution to understanding pain, it emphasized central neural mechanisms. The dorsal horns were in focus, where dynamic activities such as inhibition, excitation and modulation occurred. The brain was accepted as an active system that filtered, selected and modulated input (Melzack, 1999). Second, it also impacted on the way we conceive pain, by recognizing pain as a psycho-physiological phenomenon. In an example of a Kuhnian shift of paradigm, the gate control theory integrated neuro-physiological and psychological aspects of pain into the biomedical model. According to the gate control theory, pain is not considered somatic or psychogenic but both factors have potentiating and moderating effects. Pain management is based on these various pain models. The focus was long on curing pain. Only more recently has the emphasis shifted from pain relief to pain management, with a parallel shift from a specific focus on pain to pain-associated dysfunction.

1.3.3. Bio-psycho-social models

The gate-control theory formed the physiological basis of the **bio-psycho-social model** of pain. The bio-psycho-social model views pain as an interaction of biological, psychological and social phenomena. Models that fall under the bio-psycho-social model have proven particularly useful in

extending our knowledge about pain in those cases where pain persists in the absence of identifiable tissue damage or organic pathology. There are several variations of the bio-psycho-social model (Fordyce, 1976, Engel, 1977, Loeser, 1982).

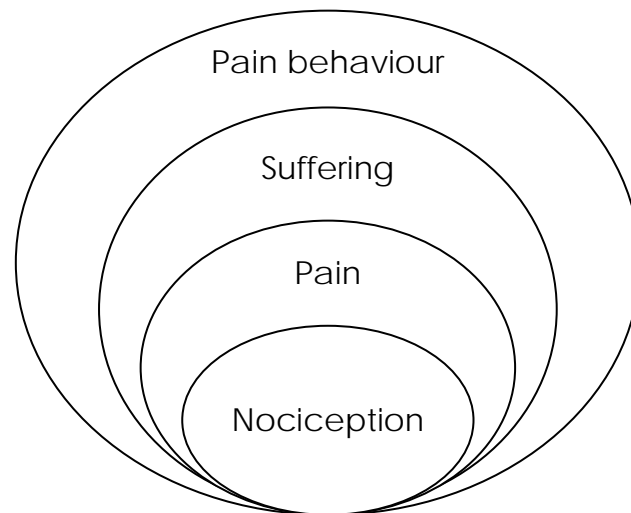


Figure 3. A schematic diagram of the bio-psycho-social model.

Fordyce was the one who first used the model in a clinical setting. By applying the mechanisms of the gate-control theory and the operant conditioning principles of Skinner (1953), Fordyce shifted the goal of treatment from reduction of pain intensity towards the impact of pain on life and the restoration of functional behaviour (Fordyce, 1976). Operant learning of avoidance behaviour was at the heart of this model, meaning that following an acute injury, avoidance behaviour is negatively reinforced through the reduction of suffering associated with nociception. Fordyce et al. (1982) outlined behavioural interventions designed to modify the learned avoidance behaviour and, finally, to reduce the disability associated with persistence. In the operant formulation, behavioural manifestations rather than pain per se are central. Fordyce's application was a revolutionary way of thinking about persistent pain. Unfortunately, this way of thinking also led to misunderstandings, such as the erroneous idea that pain behaviour is a deliberate strategy that occurs whenever the benefits outweigh the costs (Eccleston et al., 1997). The operant conditioning model of pain has been criticized for its exclusive focus on motor pain behaviours, failure to consider the emotional and cognitive aspects of pain (Schmidt, 1985, Turk and Flor, 1987, Schmidt et al., 1989) and failure to treat the subjective experience of pain (Kotarba, 1983). Based on the work of Fordyce, other models were

brought forward that take both classical and operant conditioning components (Linton et al., 1984) as well as cognitive-behavioural component in to account (Turk and Kerns, 1983). Affective factors, particularly fear, have proven to be central to the more recent bio-psycho-social models of pain, known as fear-avoidance models.

1.3.4. Fear-avoidance models

Fear-avoidance in the context of pain refers to the avoidance of movements or activities based on fear. In “*the fear-avoidance model of exaggerated pain perception*” Lethem et al. (1983) managed, for the first time, to describe a connection between pain and fear to behaviour through avoidance learning. The idea of a relationship between fear and pain is however not new, but has been known since the days of Aristotle (Eysenck, 1997).

The **central concept** of Lethem’s model is **fear of pain**. There are two extremes of coping response available to the individual, namely confrontation and avoidance. Confrontation leads to a reduction of fear with time, while avoidance leads to maintenance and exacerbation of fear. This model is an attempt to explain how and why some individuals develop a larger extent of psychological suffering to pain than others do. Avoidance motivated by fear has two components: avoidance of pain experience (cognitive avoidance) and avoidance of painful activities (behavioural avoidance). Lethem’s model was criticized and elaborated on by other authors (Slade et al., 1983, Philips, 1987, McCracken et al., 1992, Waddell et al., 1993).

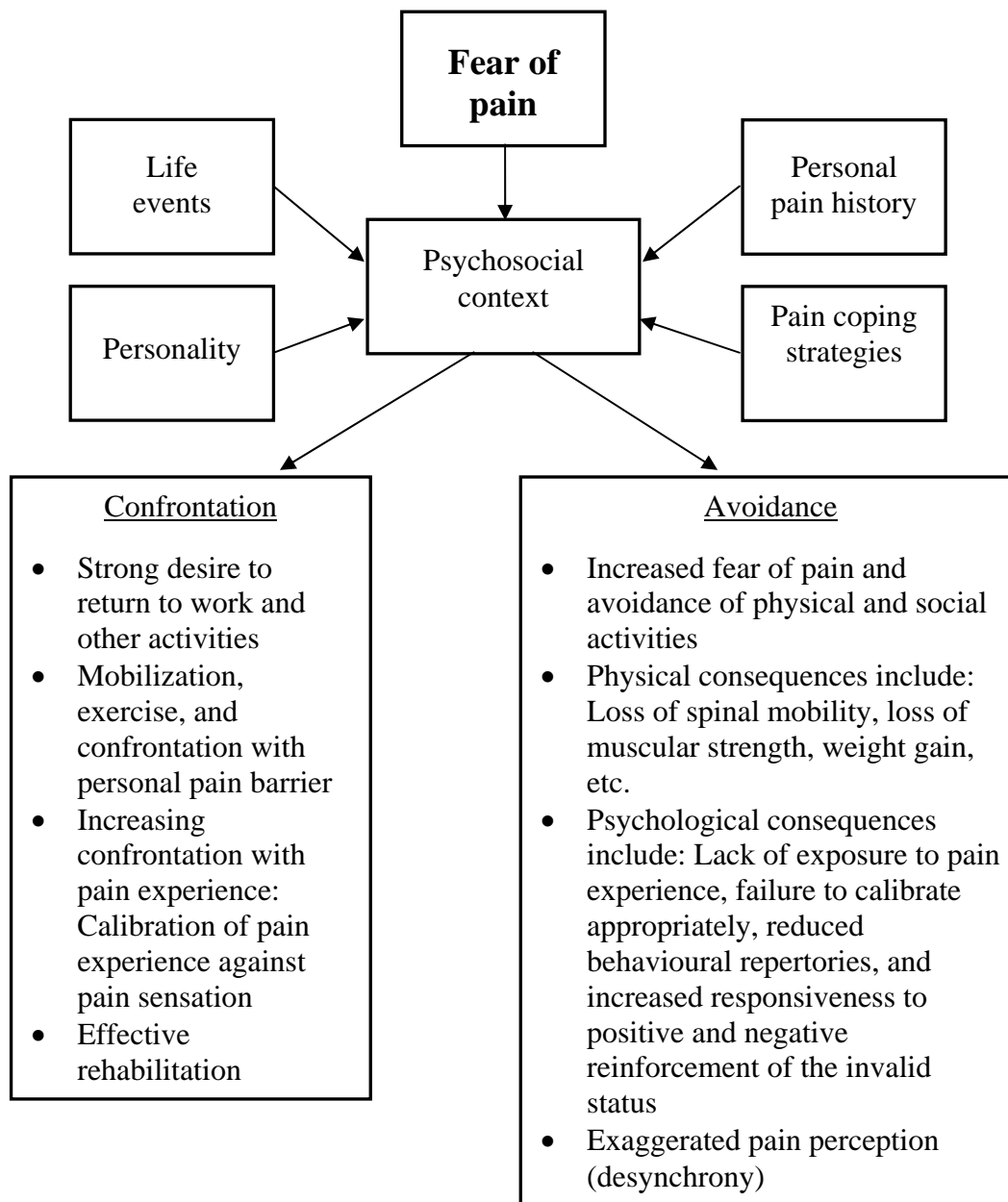


Figure 4. A fear-avoidance model of exaggerated pain perception. Reprinted from *Behav Res Ther*, 21, Lethem et al., *Outline of a fear-avoidance model of exaggerated pain perception-I*, 401-408, Copyright (1983), with kind permission from Elsevier.

The cognitive-behavioural fear-avoidance model presented by Vlaeyen et al. (1995) explained how an injury when interpreted as threatening (= catastrophizing) leads to the more **specific fear that physical activity will cause reinjury** (also called fear of movement), subsequently **avoidance behaviour** which finally leads to **disability, disuse and depression** (Figure 5). Pain catastrophizing plays a central role in the fear-avoidance model and has been defined as “an exaggerated negative mental set brought to bear

during actual or anticipated painful experience” (Sullivan et al., 2001). Vlaeyen’s model introduced the concept fear of movement/ (re)injury. In the model presented here (Figure 5) the concepts of kinesiophobia and pain-related fear are situated together with the original concept fear of movement. Vlaeyen’s model has been supported, criticized, and elaborated on (Linton and Buer, 1995, Crombez et al., 1996, Asmundson et al., 1997, Asmundson et al., 1999, Vlaeyen and Linton, 2000, Kronshage et al., 2001). In subsequent models other constructs such as negative affectivity (Vlaeyen and Linton, 2000), anxiety sensitivity (Norton and Asmundson, 2003) and hypervigilance (Vlaeyen and Linton, 2000) have been incorporated. The interrelationship between the variables in the model is still unclear.

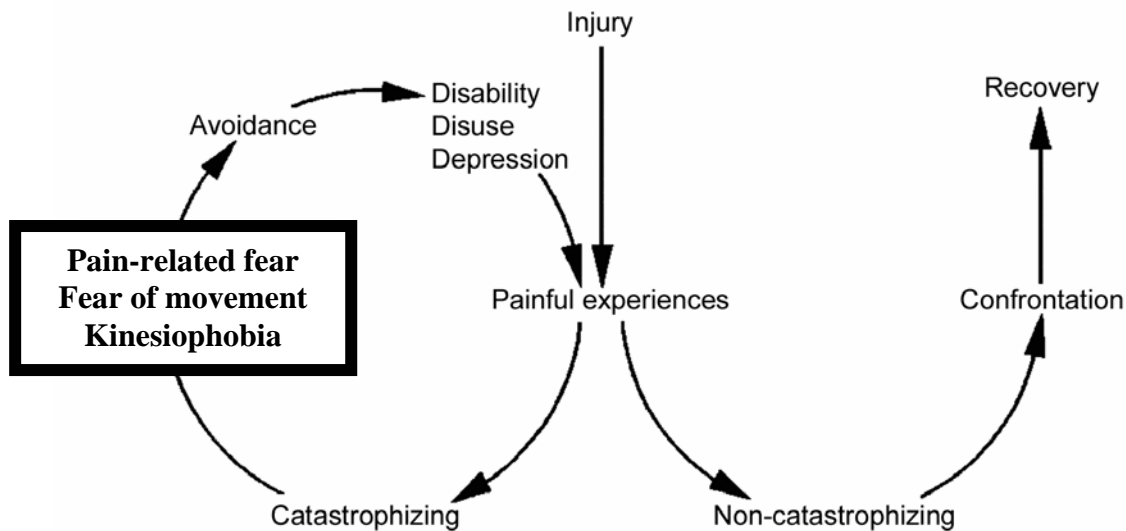


Figure 5. A cognitive-behavioral model of fear of movement/(re)injury by Vlaeyen et al. Reprinted from PAIN, 62 (3), Vlaeyen et al., Fear of movement/(re)injury in chronic low back pain and its relation to behavioral performance, 363-372, Copyright (1995), with kind permission from the International Study of Pain.

Taken together, musculoskeletal pain is natural condition that most people experience at some point in life. Pain is a complex subjective experience that involves sensory, emotional and cognitive components. These components can be found in all types of pain regardless of its origin. They interplay differently at various stages of the pain process and in different individuals. The affective and the cognitive components are the more distinct in the persistent phase. Affective factors, particularly fear, have proven to be central in the explanation and understanding of persistent pain.

2. Kinesiophobia

The introduction of the concept kinesiophobia in the field of pain (Kori et al., 1990) triggered a revival of research regarding the connection between fear, pain and avoidance behaviour in close relation to movement. Kinesiophobia was originally defined as a condition in which a patient has “*an excessive, irrational, and debilitating fear of physical movement and activity resulting from a feeling of vulnerability to painful injury or reinjury*” (Kori et al., 1990). The phenomenon was thereafter elaborated on by Vlaeyen et al. (1995, 1995), who preferred to describe the phenomenon as fear of movement/(re)injury, a specific fear of movement and physical activity that is (wrongfully) assumed to cause reinjury. The attentive reader notices that kinesiophobia was defined in 1990. It was, however, Vlaeyen et al. (1995, 1995) who in 1995 placed the phenomenon in a theoretical model.

The terms kinesiophobia, fear of movement and pain-related fear are used synonymously in the literature although there is a psychological difference between the constructs. In the most extreme situation of fear of movement, the expression “kinesiophobia” is used (Kori et al., 1990). Asmundson and Taylor (1996) and Crombez et al. (1999) referred to the phenomenon as pain-related fear. Pain-related fear is a broader and more general term, which incorporates all kind of fears related to pain. Closely related but less frequently used concepts include “fear-avoidance beliefs” (Waddell et al., 1993) and “pain-related fear-avoidance beliefs” (Balderson et al., 2004).

The definition of Kori et al. (1990) is the conceptual definition used in this thesis. However, since the three concepts are used interchangeably in the literature it is difficult to keep a strict definition and the concepts are therefore used as used by the various authors.

Table 1. The original conceptual definitions of pain-related fear, fear of movement and kinesiophobia.

Pain-related fear	Fear of movement	Kinesiophobia
Asmundson* et al, 1996	Vlaeyen et al, 1995	Kori et al, 1990
Incorporates fear of pain, fear of injury, fear of physical activity and so forth.	a specific fear of movement and physical activity that is (wrongfully) assumed to cause reinjury.	an excessive, irrational, and debilitating fear of physical movement and activity resulting from a feeling of vulnerability to painful injury or reinjury.

* Asmundson et al. were the first who mentioned the term *pain-related fear*. There is, however, no conceptual definition per se for *pain-related fear*.

2.1. Classification and definitions of fear, anxiety and phobia

Pain and fear are constructs rather than diseases or other pathological states (McNeil and Wovles, 2004). From a scientific and a clinical perspective these constructs are best conceptualized as responses, most commonly manifested as patterns of behaviour. Kinesiophobia, fear of movement and pain-related fear are all constructs designed by researchers to describe a syndrome. The constructs are what the researchers define them to be, usually referred to as conceptual definitions. Other examples of constructs include depression and anxiety. Since there is a close relationship between fear, anxiety and phobia, the constructs are explained in detail.

Fear is one of the basic and pure emotions. Per definition fear is the usually unpleasant feeling that arises as a normal response to realistic danger (Marks, 1987). Emotions such as fear are response syndromes not defined by any single feeling or behaviour but can be recognized from their typical evoking stimuli, response patterns, and courses. Fear is a multifaceted phenomenon and the features of the emotion fear are cognitive-subjective, physiological, and motor-behavioural (Lang, 1968). Long before the field of psychology was conceived, the power of fear to alter human behaviour was widely recognized. Fear is a major psychological response to a perceived threat and can be related to chronic illness (Santavirta, 1997). Fear and anxiety related to pain have been classified into three dimensions (Vlaeyen et al., 1995): fear of nociceptive stimulation or fear of the pain itself (Lethem et al., 1983, Vlaeyen and Linton, 2000), fear of pain-causing activities (Waddell et al., 1993), fear of movement and (re)injury (Kori et al., 1990, Vlaeyen et al., 1995). Fear of movement and physical activity is related to assumptions on the part of the patient that the pain will delay healing or cause (re)injury.

Anxiety is an emotion similar to fear, but arising without any objective source of danger (Marks, 1987, First and Tasman, 2004). Fear and anxiety tend unfortunately, to be used interchangeably, although there is evidence showing the distinctiveness of these constructs (McNeil et al., 1993, Craske, 1997, Barlow, 2002). Anxiety sensitivity is a personality trait conceptualized as the fear of anxiety-related sensations (Reiss et al., 1986, McNeil et al., 1993, Taylor, 1995, Craske, 1997, Barlow, 2002), which has been suggested mediate the relationship between fear of pain and pain experience (Asmundson and Taylor, 1996).

A phobia is fear of a situation that is out of proportion to its danger, can neither be explained nor reasoned away, is largely beyond voluntary control, and leads to avoidance of the feared situation (Marks, 1987). According to the Diagnostic and Statistical Manual of the American Psychiatric Association,

fourth edition (DSM-IV) (First and Tasman, 2004), a specific phobia is a circumscribed, persistent and unreasonable fear of a particular object or situation. In the case of kinesiophobia, the persistent and unreasonable fear would be fear of movement. Exposure to the phobic stimulus is associated with an acute and severe anxiety reaction. As a result, people with specific phobia often adjust their lives to avoid or minimize such contact, although they realize that their fear is unreasonable. The group “specific phobia” is heterogeneous and is often divided into subgroups. The DSM-IV has defined four subgroups on the basis of type of the stimulus: animal, situational, blood injury and nature-environmental phobia. According to Merckelbach et al. (1996) the classification of specific phobias might be even more complex. Within each of the DSM-IV subtypes some variation has been observed.

There is an ongoing debate as to whether kinesiophobia is really a phobia or a fear. Vlaeyen et al. (2004) compared the major features of specific phobia and pain-related fear in chronic pain according to the DSM-IV and, in line with Kori’s original theory, found many similarities. One point at which specific phobias and pain-related fear differ is that people with a phobia are aware that the fear is excessive and irrational, while most patients with pain reporting pain-related fear are convinced that their avoidance has a protective function and is in no way excessive.

Table 2. Differences and similarities between specific phobia and pain-related fear (according to DSM-IV). From Vlaeyen, De Jong, Sieben and Crombez in Psychological Approaches to Pain Management, Turk and Gatchel, The Guilford Press, 2002. Reprinted with kind permission from Guilford Press.

Specific phobia	Pain-related fear
1. Marked and persistent fear that is excessive or unreasonable cued by the presence or anticipation of a specific object or situation.	1. Marked and persistent fear that is (often) excessive and unreasonable, cued by the presence or anticipation of a <i>pain-eliciting situation</i> .
2. Exposure to the phobic stimulus almost invariably provokes an immediate anxiety response, which may take the form of a situational predisposed panic attack.	2. Exposure to the pain-eliciting stimulus almost invariably provokes an immediate anxiety response, including <i>avoidance/escape behaviours, increased arousal levels and hypervigilance</i> .
3. The person recognizes that fear is excessive or unreasonable.	3. The person often <i>does not</i> recognize that the fear is excessive or unreasonable.
4. The phobic situation is avoided or else is endured with intense anxiety or distress.	4. The phobic situation is avoided or else is endured with intense anxiety or distress.
5. The avoidance, anxious anticipation, or distress in the feared situation(s) interferes significantly with the person's normal routine, occupational (or academic) functioning, or social activities or relationships, or there is marked distress about having the phobia.	5. The avoidance, anxious anticipation, or distress in the feared situation(s) interferes significantly with the person's normal routine, occupational (or academic) functioning, or social activities or relationships, or there is marked distress about having the <i>pain problem</i> .
6. In individuals under 18 years, the duration is at least 6 months.	6. <i>Not considered relevant</i> .
7. The anxiety, panic attacks, or phobic avoidance associated with the specific object or situation are not better accounted for by another mental disorder.	7. The anxiety, panic attacks, or phobic avoidance associated with the specific object or situation are not better accounted for by another mental <i>or physical</i> disorder.

2.2. Kinesiophobia and avoidance behaviour

According to Vlaeyen's fear-avoidance model (Figure 5) fear of movement leads to avoidance behaviour. According to Philips, avoidance is the most prominent component of pain behaviour (Philips, 1987). In clinical terms avoidance means that an individual in pain may no longer perform certain activities because she/he anticipates that these activities will increase pain and suffering (Vlaeyen et al., 1995). Fear of movement/(re)injury has been reported to be strongly associated with activity limitations (Vlaeyen et al., 1995, Vlaeyen et al., 1995, Crombez et al., 1999). In a cross-sectional study designed to identify potential predictors of avoidance behaviours, Crombez et al. (1998) supported the fear-avoidance model by showing that avoiders were more afraid of pain, more afraid of (re)injury and reported more disability than confronters.

As a response to acute injury, avoidance behaviour is adaptive (Wall, 1979, Philips, 1987). In acute low back pain, pain behaviours can be viewed as an appropriate adaptive reaction to nociceptive stimuli (Fordyce et al., 1984). In persistent low back pain, however, avoidance behaviour is considered exaggerated maladaptive operant (learned) behaviour influenced by pain-related fears and wrongly held disability beliefs (Vlaeyen et al., 1995, Vlaeyen et al., 1995, Vlaeyen and Linton, 2000). The avoidance behaviour is extensive and complex, and includes avoidance of stimulation, movement, activity, social interactions, and leisure pursuits (Anciano, 1986, Philips and Jahanshahi, 1986, Philips, 1987).

Both cognitive avoidance and behavioural avoidance lead to a number of negative physical and psychological health consequences such as disability, disuse syndrome and depression. Longstanding avoidance and physical inactivity have negative consequences. In the scope of this thesis I am particularly interested in the consequences of avoiding physical activity.

Table 3. *Definitions of physical activity, physical exercise and physical fitness, adapted from Casparsen, Powell and Christenson, 1985 and Pate et al, 1995.*

Physical activity	Physical exercise	Physical fitness
Any bodily movement produced by skeletal muscles that results in energy expenditure.	A subset of physical activity that is planned, structured, repetitive and purposeful in the sense that improvement or maintenance of physical fitness is the objective.	Includes cardiorespiratory fitness, muscle strength, body composition and flexibility, composing a set of attributes that people have or achieve that relates to the ability to perform physical activity.

Physical activity is defined as any bodily movement produced by skeletal muscles, that results in energy expenditure (Table 3). Movement is a central component of both physical activity and physical exercise.

2.2.1. Physiological consequences of avoidance behaviour

One factor of avoidance behaviour is the avoidance of physical activity. The negative consequences of physical inactivity have been known since ancient times (Maimonides 1199 AD). Even so, in 1794 Hunter proposed the orthopaedic principle of rest as a treatment principle. The treatment principle of rest gained believers, although it was recognised that bed rest created problems. It took a century until a change was suggested, when Jones and Lovett gave a contradictory piece of advice in 1926: “*as soon as possible movement must be encouraged and bed forbidden*” (Allan and Waddell, 1989). Unfortunately, the suggestion was not widely accepted, and rest was, and still is, recommended for patients with musculoskeletal pain.

There is no definitive definition of physical inactivity in the literature. However, if the recommendation of physical activity is at least 30 minutes of accumulated physical activity per day for an adult, then the state of physical inactivity can be expressed as accumulated physical activity less than 30 minutes a day (Cider, 2005). Physical inactivity leads to deterioration of many bodily functions (Kottke, 1966) involving both physical deconditioning (Mayer and Gatchel, 1988, Wagenmakers et al., 1988) and guarded movements (Watson et al., 1997), finally resulting in the “disuse syndrome” (Bortz, 1984).

Disuse has been defined as performing at a reduced level of physical activity in daily life (Verbunt et al., 2003). Deconditioning is thought to be both a cause (Gordon, 1990, Wittink et al., 2000) and a consequence of back pain (Mayer, 1987, Kohl et al., 1988, Mayer and Gatchel, 1988, Jackson et al., 1990, Hurri et al., 1991, Hultman et al., 1993, Hupli et al., 1997, Crombez et al., 1998, Wittink et al., 2000). The term deconditioning syndrome was introduced by Mayer and Gatchel (1988) to refer to a final stage of the interaction between physical and psychological deconditioning. The characteristics of the disuse syndrome are cardiovascular vulnerability (Morris et al., 1953, Fletcher et al., 1996) obesity, musculoskeletal fragility, depression and premature aging. Verbunt (2004) has clarified the similarities and differences between the concepts disuse, deconditioning and the disuse syndrome.

It is not clear what disability stands for in the various fear-avoidance models. In this thesis disability is referred to as “the limitations of a person’s

performance compared with the performance of a fit person (daily activity and social life)” (Fairbank et al., 1980). A more elaborate definition is given by the International Classification of Functioning, Disability and Health (ICF), developed by the World Health Organisation (2001). The ICF organizes information about disability in to functioning and disability, and contextual factors. In ancient times little attention was paid to any form of disability, since people could not gain anything from being disabled (Allan and Waddell, 1989). The first evidence of low back pain disability came after the introduction of railways (Allan and Waddell, 1989). According to Allan and Waddell, the medical profession’s struggle with the problems of disability coincided with the development of psychology as a discipline.

Both the negative effects of inactivity and the positive effects of physical activity have been well documented (Bortz, 1984, Radin, 1986, Gärdsell et al., 1991, Järvinen and Lehto, 1993, Pedersen and Saltin, 2006).

2.2.2. Psychological consequences of avoidance behaviour

Avoidance behaviour also has psychological consequences such as depression and frustration. Both depression and disuse are known to be associated with decreased pain tolerance (Romano and Turner, 1985, Menard et al., 1994). Psychological factors may also act indirectly on pain and disability by reducing physical activity and consequently reducing muscle strength, flexibility, tone and endurance. Fear of re-injury, loss of disability compensation and job dissatisfaction can also influence the individuals’ disability (Turk, 1999). Bortz (1984) described the psychological consequences of the disuse syndrome as a result of inactivity, whereas Mayer and Gatchel (1988) described psychological deconditioning as a reaction to both pain and inactivity. The positive effects of physical activity are known to be well-functioning treatment strategies for depression (McCann and Holmes, 1984, Martinsen et al., 1985, Martinsen et al., 1989, Craft and Landers, 1998), although there are some contradictory findings as well (Lawlor and Hopker, 2001).

2.3. The occurrence of kinesiophobia

The prevalence of all kinds of pain-related fear, included kinesiophobia, was poorly understood at the time of designing this thesis. Today, however new knowledge has been gained. Buer and Linton (2002) demonstrated that fear-avoidance beliefs are present in a general population with non-persistent pain. Buer et al. (2003) showed that higher fear-avoidance beliefs and catastrophising increased the risk of having pain at follow-up, and in patients

with fractures not having regained full muscle strength.

Taken together, fear is a normal response to pain. Kinesiophobia is not a disease or a diagnosis, but a construct put together to describe a debilitating fear of physical movement. Kinesiophobia leads to avoidance behaviour, which in turn leads to negative consequences both physiologically and psychologically. In a clinical setting fear of movement and fear of the outcome of surgical procedures are well known. Even so, little is known about the occurrence about kinesiophobia among patients in an orthopaedic setting, or among patients that seek care at a physical therapy department.

3. Kinesiophobia and rehabilitation

This thesis does not evaluate any rehabilitation intervention, but since kinesiophobia is said to play a negative role in the outcome of rehabilitation of musculoskeletal pain (Kori et al., 1990, Vlaeyen et al., 1995, Vlaeyen et al., 1995, Vlaeyen and Crombez, 1999, Vlaeyen et al., 1999), it must be placed in its' context.

3.1. Rehabilitation strategies for kinesiophobia

First, a systematic application of graded activity (also called operant graded activity), as described by Lindström et al. (1992) and based upon the principles of Fordyce (1976), was suggested as a suitable treatment for kinesiophobia (Vlaeyen et al., 1995). However, since exposure is considered the treatment of choice for phobias (Dolce et al., 1986, Philips, 1987) cognitive-graded exposure became the choice of rehabilitation strategy. A cognitive-graded exposure is quite similar to the operant graded activity program in that it gradually increases activity levels despite pain (Fordyce et al., 1982, Dolce et al., 1986, Fordyce et al., 1986, Philips, 1987, Lindström et al., 1992). However, both conceptually and practically exposure in vivo is different from graded activity.

Graded activity is based on instrumental learning principles, unlike exposure that is currently viewed as a cognitive process in which fear is activated, catastrophic expectations are challenged and disconfirmed (Vlaeyen et al., 2004). The dissimilarities are that the graded exposure program pays special attention to the specific aspects of the pain-related stimuli. For example if the patient fears walking on rough ground, then the graded exposure should include an activity that mimics that specific activity. Craske and Rowe (1997) suggested that experiencing behaving differently is far more convincing than rational argument. In relation to fear of movement it is important for the patient to experiencing the movement, and not simply being

told to stay physically active. It is also far more convincing for patients with high degree of pain-related fear to actually feel that they can perform an avoided activity with little or no pain than just be told that they can actually do it (Al-Obaidi et al., 2003).

Based on the principles described above, Vlaeyen et al. (2001) developed a cognitive exposure in vivo treatment for patients with chronic low back pain with fear and avoidance related functional problems. Dramatic improvements in pain-related fear, catastrophizing and disability were found (Vlaeyen et al., 2001, Vlaeyen et al., 2002). These findings were replicated by Linton et al. (2002) who, however, reported difficulties in executing the exposure. Further support for the exposure technique in relation to patients with back pain was reported by Boersma et al. (2004). These three studies were all single subject designs. In all of the studies described above, the physical therapist had a central role in guiding the patient through the intervention.

3.2. The role of the physical therapist in relation to kinesiophobia

Physical therapists are the occupational group that most frequently comes into contact with patients suffering from musculoskeletal pain (Thornquist, 1994, Brinck et al., 1995, Nygren and Lisspers, 1999, Åsenlöf, 2005). The physical therapist is often a central person throughout the entire rehabilitation process.

According to the Swedish Association of Registered Physiotherapists, physiotherapists should work with prevention, examination, treatment and rehabilitation of movement disorders that limit or threaten to limit movement capacity of the individual and also develop methods and quality aspects as well as evaluate outcomes (LSR, 1997). The physical therapist guide patients with pain through rehabilitation programs in various settings. Nicholas et al. (1991) have shown that a combination of psychological treatment and physical therapy treatment works better than physical therapy alone. When it comes to kinesiophobia the role of the physical therapist has not been investigated, but the physical therapist has had a central role in the rehabilitation programs that have been proven effective (Vlaeyen et al., 2001, Linton et al., 2002, Vlaeyen et al., 2002, Boersma et al., 2004).

Taken together, kinesiophobia is said to play a negative role in the outcome of rehabilitation of musculoskeletal pain. Since physical therapists are involved in the rehabilitation process, kinesiophobia is an important phenomenon to study. It is, however, of importance to describe a condition thoroughly before starting to design rehabilitation programs. In order to describe this condition a reliable and valid measure was needed.

4. Assessment of kinesiophobia

Assessment is the first step in the process of rehabilitation, and it is important for identification and quantification of problems the individual may have, and of factors relevant to the resolution of the problems (Wade, 1998). Before starting a rehabilitation program, screening for *pain-related fear* is warranted (Linton and Hallden, 1998, Vlaeyen et al., 2001, Linton, 2002). It is important to stress that pain management is not only carried out at pain clinics. In Sweden, pain management is performed also performed in primary health care and in orthopaedic care. Screening with “psychosocial yellow-flags” has been found to be an effective tool for early selection of patients with a poor prognosis (Linton and Hallden, 1998). The fear-avoidance model may serve as a useful theoretical framework for early screening and intervention.

Clinicians need screening devices that can be quickly and easily administered and scored. Such devices enable the clinician to screen out patients who require more thorough psychological evaluation and possible treatment by a clinical psychologist (Parker et al., 1995). I deliberately do not define the profession of the clinician. In my opinion, in relation to rehabilitation of musculoskeletal pain, it could be a physician, a psychologist or a physical therapist. Pain is a subjective experience and there has until recently been no objective way to assess pain. New techniques such as functional imaging has enabled us objectify the pain experiences (Ingvar, 1999, Petrovic, 2002). The only way, however, we know about an individual’s experience of pain, in a clinical setting, is by how they communicate verbally or from their non-verbal behaviour.

Pain behaviour can be assessed across three broad domains (Cone, 1978), including cognitive-affective, overt-motoric, and physiological. These domains may be covered using various methods. The methods available are self-report, observation by others and instrument/apparatus (Waddell et al., 1980, Keefe, 1982, Richards et al., 1982, Slade et al., 1983, Eifert and Wilson, 1991). Pain, fear and anxiety are most often assessed in the cognitive-affective domain using verbal reporting. So far, the only way of operationalizing kinesiophobia is by using the questionnaire the Tampa Scale for Kinesiophobia, TSK (Miller et al., 1991). The TSK measures the subjective experience of kinesiophobia and was developed to discriminate between non-excessive fear and phobia among patients with persistent musculoskeletal pain.

4.1. Tampa Scale for Kinesiophobia (TSK)

The TSK was designed on the basis of clinical experiences from a pain clinic in order to discriminate between non-excessive fear and phobia among patients with persistent musculoskeletal pain. The TSK is one of the most frequently employed measures. It has been used for more than a decade and found valuable in both research and in clinical settings (Vlaeyen et al., 1995, Vlaeyen et al., 1995, Clark et al., 1996, Crombez et al., 1999, Geisser et al., 2000, Cohen et al., 2003, Gironde et al., 2003, Swinkels-Meewisse et al., 2003, Swinkels-Meewisse et al., 2003, Carter-Sand et al., 2004, Dehghani et al., 2004, Goubert et al., 2004, Nijs et al., 2004, Nijs et al., 2004, Roelofs et al., 2004, Bunketorp et al., 2005, Burwinkle et al., 2005, Houben et al., 2005, Koumantakis et al., 2005, Buitenhuis et al., 2006, Bunketorp et al., 2006, Cook et al., 2006, Swinkels-Meewisse et al., 2006, Swinkels-Meewisse et al., 2006).

Miller et al. (1991) presented the TSK as a one-dimensional 17-item scale. Thereafter six different English versions have been presented (Clark et al., 1996, Geisser et al., 2000, Cohen et al., 2003, Gironde et al., 2003, Carter-Sand et al., 2004, Burwinkle et al., 2005, Woby et al., 2005). There are four different factor models of the Dutch version of the TSK, called by three different names TSK-DV (Vlaeyen et al., 1995, Crombez et al., 1999), TSK-2 (Vlaeyen et al., 1995), and TSK (Swinkels-Meewisse et al., 2003, Swinkels-Meewisse et al., 2003, Goubert et al., 2004, Roelofs et al., 2004).

When I began this thesis there was no reliable and valid measure of kinesiophobia or pain-related fear available in the Swedish language.

4.2. Associated measure instruments of pain-related fear

Several questionnaires have been developed to measure *pain-related fears* including the Fear Avoidance Beliefs Questionnaire FABQ (Waddell et al., 1993); the Pain Anxiety Symptoms Scale PASS (McCracken et al., 1992) and the Fear of Pain Questionnaire FPQ (McNeil and Rainwater, 1998). These questionnaires measure slightly different aspects of pain-related fear. FABQ measures beliefs about possible harm resulting from physical activity and beliefs about possible harm from work-specific activities. PASS is designed to assess behaviours related to the fear of pain. FPQ reflects how much fear is associated with specific situations. A modified version of the FABQ (MFABQ) is available in the Swedish language (Buer, 2003), whereas the other measure instruments are not.

Taken together, in order to make an assessment of kinesiophobia a reliable and valid measure was needed. TSK is the only measure that identifies

kinesiophobia. At the start of this thesis there was no such measure available in the Swedish language.

5. Theoretical definitions of movement

The stem *kinesis* in the word kinesiophobia means movement. Interestingly the word *emotion* stems from the Latin *movere*, which means to act. The fascinating thing about the construct of kinesiophobia is that it combines motion and emotions in the same word.

The term movement has a variety of different meanings related to motion: physical movement between points in space ("A to B"), where the amount of movement is called distance, with a direction that becomes displacement. The rate of movement is the speed which, with direction, becomes velocity. Active movement is called locomotion and transport. In biology movement refers to both intracellular movement and the movement of the organism or its parts and organs. Our modern way of thinking about movement in relation to the body is strongly linked to Descartes' bio-medical model described above. The objective body is the bones, tissues, blood cells, and organs we have learned to regard as "body". The objective body can be described in terms of neurological, chemical and physical components (Bullington, 1999). Movement may have different meanings under different circumstances. According to biomedicine the body as biology is in focus. The body as a means of expression, the body as I-me, is easily forgotten (Rudebeck, 2000).

Maurice Merleau-Ponty (1908-1961) strongly criticized traditional philosophy and science for making the body an object. Merleau-Ponty was influenced by the phenomenological tradition and its concern and search for the essence in human experience. He was especially inspired by Edmund Husserl (1859-1938) and Martin Heidegger (1889-1976). In Merleau-Ponty's main work "*Phenomenology of Perception*" (Merleau-Ponty, 1962) the body was the essence of his philosophy. Merleau-Ponty's starting point was that a person's understanding of the world has its basis in her/his understanding of the situation or surroundings. The human body is not an object; the body is our centre and the carrier of experiences. Merleau-Ponty was also concerned with the ambiguity of the body, "the lived body" as a relationship between the body subject and the body object. Every person both *has* and *is* a body. By this he indicates that a person is simultaneously living in the relation between being a subject and an object, between seeing and being seen, between hearing and being heard and between touching and being touched.

5.1. Movement from a physiotherapeutic perspective

Movement is a central concept in physical therapy (Hislop, 1975, Kukkonen, 1987, Tyni-Lenné, 1988, Cott et al., 1995). The science of normal human motion, kinesiology (*kinesis=motion or movement*), was defined by a Swedish physical therapist by the name of Georgii as early as 1854. According to Hislop (1975), pathokinesiology is the clinical science of physical therapy. Pathokinesiology is the study of anatomy and physiology as they relate to abnormal human movement.

According to the World Confederation of Physical Therapy (WCPT), physical therapy is concerned with identifying and maximising movement potential within the spheres of promotion, prevention, rehabilitation and treatment (1999). Health promotion and disability prevention considering physical, psychological and social factors are also within the scope of the physical therapy profession (European region of the WCPT, 2003). The purpose of physical therapy is to restore motion homeostasis to the person or his subsystems or to enhance the adaptive capacities of the organism to permanent impairment or loss.

The central concepts of physical therapy are human motion and the internal relationship from the tissue level to the person level (Hislop, 1975). Therapeutic exercise is one of the basic tools physiotherapists use to help patients recover from disease, injury or illness (Hislop, 1975). Kukkonen (1987) presented the basic movements man uses in daily life as a fundamental concept in physical therapy. Movement is essential to health and is considered both as means and goal in physiotherapy (Tyni-Lenné, 1988). Tyni-Lenné presented the concepts; movement prerequisite, movement ability and movement behaviour. Cott and Finch (1995) introduced their *Movement continuum theory*, in which movement in general is said to be essential to human life; to occur on a continuum from the microscopic level to the level of the individual in society, and to be influenced by physical, psychological, social, and environmental factors. Rosberg (2000) defines physical therapy as a social process with an understanding of the body as existence, relation and meaning. Wikström-Grotell (2003) emphasized that the experiences of movements are related to health and joy of movement. From a physiotherapeutic perspective the concept of movement has been considered complex and multidimensional, with physical, mental, emotional and existential dimensions (Stenmar and Nordholm, 1994, Abrandt, 1997, Öberg, 1998, Wikström Grotell, 2000, Wikström Grotell et al., 2002).

5.2. Movement from a patient perspective

For the patient with persistent pain, movement is often accompanied by pain. During the last decade a focus has developed on the negative impact of *fear of movement* on the patient with persistent pain (Vlaeyen et al., 1995, Vlaeyen et al., 1995, Crombez et al., 1999, Vlaeyen and Linton, 2000, Swinkels-Meewisse et al., 2003). In the most extreme situation of fear of movement, the expression “kinesiophobia” is used (Kori et al., 1990). The body is central to all movement and can be seen in two ways: either as an objective body, described in terms of neurological, chemical or physical components or as the lived body, which is the embodied subjectivity of someone in particular (Merleau-Ponty, 1962).

Taken together, the concept of movement has, from a physiotherapeutic perspective, been considered complex and multidimensional, with physical, mental, emotional and existential dimensions. The “fear of movement” field of research has so far dealt with the objective body from the perspective of the researcher. By asking the patients about their experience regarding moving with pain, new knowledge can be acquired.

6. The theoretical framework of this thesis

All science is interpreted from a certain perspective, whether or not we are aware of it. It is all in the eye of the beholder, or in this case in the head of the researcher. To define from what perspective I have written this thesis will hence help the reader to follow my thinking process. A scientific *paradigm* was defined by Thomas Kuhn as “*accepted example of actual scientific practice that some particular community acknowledges for a time as supplying the foundation for its further practice*” (Kuhn, 1970). A paradigm directs your focus and is like a pair of tinted eyeglasses. Everything you see is dependent on the glasses (the paradigm) you are using. I would therefore start out by explaining from what perspective I wrote this thesis. It does not mean that anyone with another perspective not can find this useful.

So far the biomedical model seems to be the predominant model within the health care system and especially in medicine and physiotherapy (Engel, 1977, 1980, Damasio, 1994, Svenaeus, 1999, Steen and Haugli, 2000). When a person with persistent pain consults a physician or physiotherapist, they will search for objective findings to explain the cause of their pain. Linear causal thinking says: if there are no objective findings then there are no explanations for the pain. The pain is thus viewed as acultural, ahistorical and separate from the person as an active subject and being (Gamsa, 1994). This is particularly evident in an orthopaedic setting, where the biomedical focus

needs to be in focus. The problem occurs when patients with persistent pain are encountered, assessed and treated as patients with acute pain. We need to extend our knowledge about the factors we need to address in such a setting.

My perspective is that of a physical therapist, finding movement complex and multidimensional, with physical, mental, emotional and existential dimensions essential to life. In this thesis I have combined my biomedical thinking with a phenomenological perspective. I have tried to understand the phenomenon of kinesiophobia from various perspectives and I argue throughout this thesis that combining perspectives has made all the difference in the acquisition of new knowledge.

AIMS OF THE THESIS

The overall aim of this thesis was to investigate various aspects of the phenomenon of kinesiophobia among patients with musculoskeletal pain.

I. The aim of study I was to evaluate the psychometric properties of the Swedish language version of the Tampa Scale for Kinesiophobia (TSK-SV) questionnaire.

II. The aim of study II was to explore the conceptual dimensions of the TSK questionnaire based on a large Swedish sample.

III. The primary aim of study III was to describe the occurrence of kinesiophobia in patients with musculoskeletal pain.

IV. The secondary aim of study III was to investigate the association between kinesiophobia and pain variables, physical exercise measures and psychological characteristics in patients with musculoskeletal pain.

V. The aim of study IV was to explore how patients with persistent musculoskeletal pain experience moving with pain.

PATIENTS AND METHODS

7. Study population

The patients were recruited from three different orthopaedic outpatient clinics and two physical therapy departments within a primary healthcare setting in the Region Västra Götaland. The subjects in the aerobics group were recruited from five different Friskis & Sveltis' aerobics classes in the Göteborg area.

7.1. Inclusion and exclusion criteria

Inclusion criteria in all four studies were 18 to 65 years of age and non-malignant musculoskeletal pain. Exclusion criteria in all four studies were malignant pain, neurological diseases, rheumatic diseases, and inability to understand the Swedish language. The wordings vary, however, in description of the inclusion and exclusion criteria.

7.2. Patients included

For the purpose of this thesis 1304 patients, were asked to participate. Of the 1304 patients, 714 (55%) chose to participate. This study population constitutes eight subgroups, A-H (Table 4).

Table 4. A description of the patient distribution in the various subgroups included in the thesis.

Study Subgroup	I A	B	C	II D	E	F	III G	IV H	All
Request	214	112	138	293	140	28	369	*	1294
Included	102	103	94	149	91	25	140	10	714
Response rate	48%	92%	68%	51%	65%	89%	38%	*	55%

A=Persistent low back pain, orthopaedic outpatient clinic

B=Persistent leg pain, orthopaedic outpatient clinic

C=Heterogeneous persistent musculoskeletal pain, orthopaedic outpatient clinic

D=Persistent low back pain, orthopaedic outpatient clinic

E=Persistent low back pain (scheduled for surgery), orthopaedic outpatient clinic

F=Heterogeneous persistent musculoskeletal pain (long term sick listed), orthopaedic outpatient clinic

G=Heterogeneous musculoskeletal pain, primary health care

H=Heterogeneous persistent musculoskeletal pain, orthopaedic outpatient clinic and primary health care

** Not applicable to this kind of methodology*

Table 5. Description of the patients included in the thesis

Sample	Number of patients	Mean age		Pain duration
		Years	Months	Median (min-max)
		Mean (SD)		
Total	714	45 (12.3)	36 (1-624)	
Women	387	45 (12.1)	36 (1-624)	
Men	327	45 (12.6)	36 (1-468)	

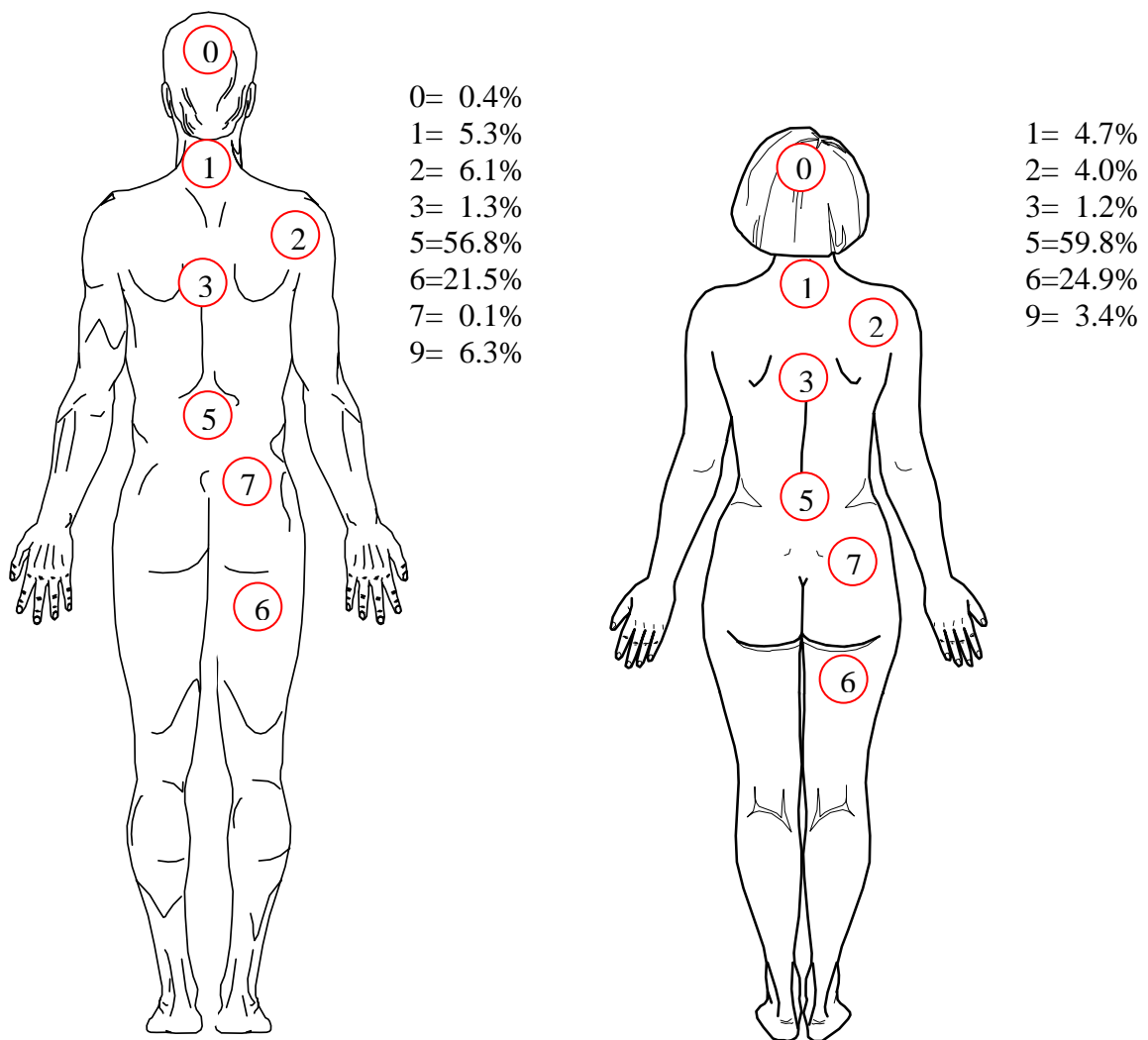


Figure 6. The distribution of pain localisations in the patients who participated in this thesis. The pain localisations were classified according to the classification of the International Association for the Study of Pain (IASP)(Merskey, 1979). The localization multiple, 9, is not defined by IASP but by the author (M.L.).

7.3. Subjects included

For the known groups' method (Study I), 60 subjects of 113 (53%), who participated in an aerobics exercise program especially designed for people with back problems (referred to as the aerobics group), completed the TSK-SV questionnaire.

7.4. Non-responders

The response rates varied in the various subgroups. The reasons for not participating are presented in Table 6, and analyzed more thoroughly in the general discussion.

Table 6. The distribution of the reasons for not participating.

Study	I	II					III	IV
Subgroup	A	B	C	D	E	F	G	H
Request	214	112	138	293	140	28	369	*
Did not fulfil criteria								
-rheumatic disease	5		3	9	5		3	
-neurologic disease	4			6	4		6	
-malignant disease	4			6	6		1	
-other diagnoses	3			8	4			
-no pain		1	1				6	
Chose not to participate	16			3		3	1	
Interpreter			3					
Incomplete address	3							
Administrative problems		8			19			
Did not respond	60		37	112	11		212	
Included	119**	103	94	149	91	25	140	

* Not applicable to this study

**The number included is different from Study I (n=102). In Study I all incomplete questionnaires (n=17) were excluded.

8. Study design

Study designs can be divided in to experimental and non-experimental designs. There are two broad classes of non-experimental research: correlational and descriptive (Portney and Watkins, 2000). All four studies have a descriptive design.

9. Measurement properties

9.1. Psychometrics

Psychometrics is the field of study concerned with the theory and technique of psychological measurement, which includes the measurement of knowledge, abilities, attitudes, and personality traits.

There has been an increasing need for sound, psychometrically based instruments in modern physical therapy. Such assessment methods should be relevant, valid, reliable, sensitive to changes in clinical conditions, easy to use and communicable (Altman, 1991). All instruments to be used in clinical practice must be examined for reliability and validity (Nunnally and Bernstein, 1994, Öberg, 1996). For pedagogical reasons, reliability and validity are divided in two separate sections below. In reality there is no clear cut between where reliability starts and validity ends.

9.2. Reliability and validity

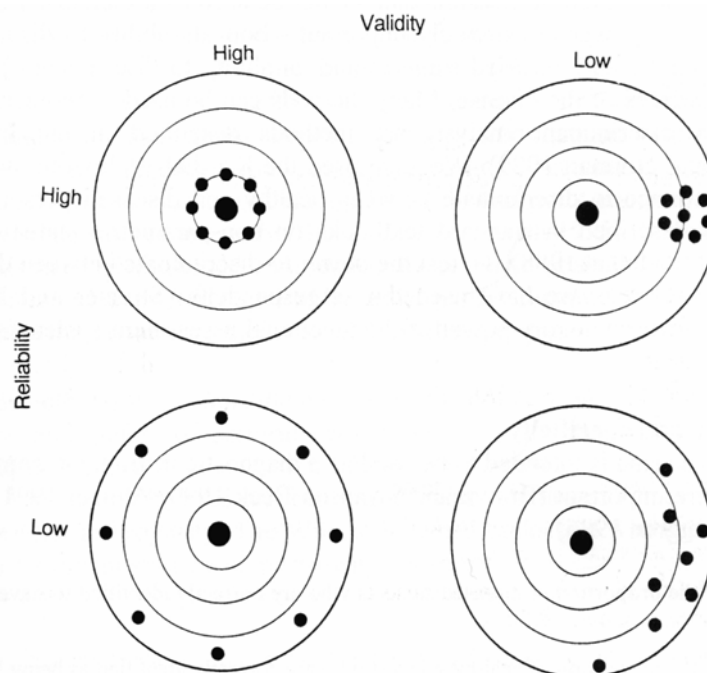


Figure 7. The relationship between reliability and validity illustrated as “target diagrams”. (A) Scores are both reliable and valid. (B) Scores are highly reliable, but not valid, demonstrating systematic error. (C) Scores are highly valid, but not reliable. (D) Scores are neither reliable nor valid, demonstrating random error. Modified after Ahlbom and Norell 1981, Öberg 1996. Published with kind permission from Studentlitteratur, Lund.

A measurement cannot be valid if it is not reliable (Cronbach, 1990, Nunnally and Bernstein, 1994, Öberg, 1996, Portney and Watkins, 2000). Reliability is a necessary but not sufficient prerequisite for validity (Nunnally and Bernstein, 1994).

9.3. Reliability

Reliability is the degree of consistency or dependability with which an instrument measures the attribute it is designed to measure (Polit and Hungler, 1999). Reliability is basically about the ability of a test to yield the same result under similar test conditions (Cronbach, 1990, Nunnally and Bernstein, 1994). At the heart of all measurement is reliability, or the extent to which a measurement is consistent and free from error. Reliability is based on the theory of measurement error. Measurement error can be a mixture of systematic and random processes. One definition of reliability is freedom from random error (Nunnally and Bernstein, 1994, Portney and Watkins, 2000). Reliability is a measure of how much of this total variance is attributable to true differences between scores. Therefore reliability can be expressed as a ratio of the true score variance to the total variance. This ratio defines the reliability coefficient (Portney and Watkins, 2000). The types of reliability estimated in this study are stability and internal consistency (Nunnally and Bernstein, 1994, Portney and Watkins, 2000).

9.3.1. Stability

Reliability can be subdivided into stability, equivalence and internal consistency. Stability measures the extent to which individual standings fluctuate. If there is a systematic change over time, the scores lack stability (Cronbach, 1990). The test-retest procedure is one way of measuring stability. With the test-retest method, the same test is administered twice to the same group, normally with an interval of a couple of weeks between administrations. Equivalence assesses the degree of similarity between alternate forms of a measuring instrument (Polit and Hungler, 1999). A variant of the test-retest method is to use two equivalent versions of a test, administered simultaneously. Forms are equivalent if they have essentially similar content, structure, and statistical properties. Correlating equivalent forms estimates a reliability coefficient (Cronbach, 1990).

9.3.2. Internal consistency

Internal consistency is an indicator of how well the individual items of a scale reflect a common, underlying construct (Spector, 1992, Portney and Watkins,

2000). With regard to TSK-SV internal consistency shows how well the 17 items reflect kinesiophobia. If the test items are reliable, they should reflect the test taker's true score, and any variance should solely be attributable to differences between subjects, not to error. The stronger the intercorrelations are among a test's items, the greater its homogeneity. An internal-consistency index ordinarily reflects both homogeneity and test length (Cronbach, 1990). Internal consistency is usually measured by the alpha coefficient, also known as Cronbach's alpha (Cronbach, 1951).

9.4. Validity

This thesis deals with measurement validity which is separate from design validity. Design validity, as the name implies, is about the validity of a research design and includes statistical conclusion validity, internal validity, construct validity of causes and effects, and external validity (Portney and Watkins, 2000).

Measurement validity concerns the extent to which an instrument measures what it is intended to measure (Nunnally and Bernstein, 1994, Polit and Hungler, 1999, Portney and Watkins, 2000). Unlike reliability, the validity of an instrument is extremely difficult to establish (Kline, 1998, Polit and Hungler, 1999). Like reliability, validity has a number of different aspects and assessments approaches. Validity implies that a measurement is relatively free from error. In other words, a valid test is also reliable. Although reliability is a prerequisite for validity, this relationship is unidirectional; that is, reliability sets the limit of validity, but is no guarantee of it. Like reliability, validity is not inherent to an instrument but must be evaluated in the context of the test's intended purpose and a specific population (Portney and Watkins, 2000). Whether or not a test is valid or not is ultimately a matter of opinion in the light of the evidence about its validity (Kline, 1998). Like reliability, validity is a matter of degree rather than an all-or-none property, which makes validation an unending process (Nunnally and Bernstein, 1994, Portney and Watkins, 2000).

Validity can be divided into different components, the terminology of which is not clear cut (Svensson, 1993, Nunnally and Bernstein, 1994, Kline, 1998, Polit and Hungler, 1999, Portney and Watkins, 2000). The types of validity used to collect evidence for the validity of TSK-SV were face validity, content validity, and construct validity (Portney and Watkins, 2000).

9.4.1. Face validity

Face validity, the weakest form of validity, refers to whether or not the instrument appears to be measuring the appropriate construct.

9.4.2. Content validity

Content validity, also known as intrinsic validity, circular validity and relevance validity, indicates that the items that make up an instrument adequately sample the universe of content that defines the variable being measured (Nunnally and Bernstein, 1994, Kline, 2000, Portney and Watkins, 2000).

9.4.3. Construct validity

Cronbach and Meehl (1955) introduced the concept of construct validity. The term “construct” is virtually synonymous with “concept” (Kline, 2000). The construct in this context is kinesiophobia. Construct validity, also called trait validity and factorial validity, establishes the ability of an instrument to measure an abstract construct and the degree to which the instrument reflects the theoretical components of the construct (Nunnally and Bernstein, 1994, Portney and Watkins, 2000). Convergent validity is used to specify how closely related similar scales are in measuring the same variable. Convergent validity is a sub-concept of construct validity (Svensson, 2000).

10. Measurements

In this thesis self-reported measurements were used in Studies I, II, and III. A summary the questionnaires used in each study are presented in Table 7.

Table 7. A summary of the questionnaires used in the thesis.

Variables	Measured using	Study			
		I	II	III	IV*
Kinesiophobia	Tampa Scale for Kinesiophobia	●	●	●	
Depressed mood	Beck Depression Inventory			●	
Physical disability	Disability Rating Index		●	●	
Fear-avoidance beliefs	Fear-Avoidance Beliefs Questionnaire		●	●	
General fear (fullness)	Fear Survey Schedule		●		
The psychosocial and behavioral consequences of pain	Multidimensional Pain Inventory			●	
General anxiety	State and Trait Anxiety Inventory		●		
Pain intensity	Visual Analogue Scale		●	●	
Pain duration	Self-reported, in months		●	●	
Pain localisation	Pain drawing		●	●	
Physical exercise	Yes/No			●	

* Not applicable to this study

10.1. Tampa Scale for Kinesiophobia (TSK-SV)

Kinesiophobia was measured using the Swedish version of the TSK (Lundberg et al., 2004). The TSK questionnaire comprises 17 items assessing the subjective rating of kinesiophobia. Each item has a 4-point Likert scale with scoring alternatives ranging from “strongly disagree” to “strongly agree”. A total sum is calculated after inversion of the individual scores of items 4, 8, 12 and 16. The total scores vary between 17 and 68. A high TSK value indicates a high degree of kinesiophobia.

The original English version of TSK has been evaluated with respect to reliability and validity (Clark et al., 1996, Geisser et al., 2000, Cohen et al., 2003, Gironda et al., 2003, Carter-Sand et al., 2004, Burwinkle et al., 2005, Woby et al., 2005). TSK has demonstrated good internal consistency and test-retest stability (Woby et al., 2005). Miller et al. (1991) presented TSK as a one-dimensional 17-item scale. Clark et al. (1996) presented a 13-item version with two factors called “Fear of Harm” and “Pathophysiological

Beliefs”. Geisser et al. (2000) replicated the factor structure of the model reported by Clark et al. (1996) with the exception of one item. Cohen et al. (2003) found a two-factor model comprised of 12 items, which they called TSK-R. These results were confirmed by Gironde et al. (2003). Carter-Sand et al. (2004) provided support for the convergent validity of Clark’s two factor model. Recently Woby et al. (2005) presented a one-factor 11-item version. Burwinkle et al. (2005) went even further and provided support for a one-factor, four item model.

The Dutch version of the TSK (TSK-DV) has also been evaluated with respect to reliability and validity (Vlaeyen et al., 1995, Swinkels-Meewisse et al., 2003, Swinkels-Meewisse et al., 2003, Goubert et al., 2004, Roelofs et al., 2004). TSK-DV demonstrated good internal consistency (Vlaeyen et al., 1995, Vlaeyen et al., 1995, Crombez et al., 1999, Swinkels-Meewisse et al., 2003) and test-retest stability (Swinkels-Meewisse et al., 2003). There are four different factor models of the Dutch version of the TSK, called TSK-DV (Vlaeyen et al., 1995), TSK-2 (Vlaeyen et al., 1995), and TSK (Vlaeyen et al., 1995, Swinkels-Meewisse et al., 2003, Swinkels-Meewisse et al., 2003, Goubert et al., 2004, Roelofs et al., 2004). Vlaeyen et al. (1995) presented a four-factor solution (TSK-2: Harm, Fear of (re)injury, Importance of exercise and Avoidance of activity) but arguments were formulated in favour of the use of the total score. Swinkels-Meewisse et al. (2003) came to the conclusion that a two-factor solution, labelled “harm” and “activity avoidance”, without the reversed items showed the best fit. Goubert et al. (2004) concluded that the two-factor model (TSK without the reversed items) of Clark et al. (1996) ought to be used in clinical practice and future research. According to Roelofs et al. (2004) a two-factor model of the TSK without the inversely phrased items had the best fit as compared with other models.

10.2. Beck Depression Inventory (BDI)

Depressed mood was measured by means of the Beck Depression Inventory (BDI) (Beck et al., 1961). The BDI comprises 21 items on a verbal descriptive scale where each item ranges from 0-3 points, summarized to a theoretical maximum of 63 points. In a clinical setting 9 is used as a cut-off score for depressed mood in a non-psychiatric population. The BDI has been widely used in clinical settings but no work has yet been published with reference to the reliability and validity of the Swedish version.

10.3. Disability Rating Index (DRI)

Physical disability was measured with the Disability Rating Index (DRI) (Salén et al., 1994). DRI is a self-administered questionnaire, where patients rate their perceived ability to perform twelve different kinds of physical activities on a 100 mm visual analogue scale. The rating options range from 0 (without difficulty) to 100 (not at all). An index is obtained by measuring the distance in mm. The mean value of these measurements provides the DRI index. The definition of a high degree of disability varies dependent upon the diagnosis. The DRI has been found to be reliable and valid for use on Swedish patients with persistent pain (Salén et al., 1994).

10.4. Fear-Avoidance Beliefs Questionnaire (FABQ)

Fear-avoidance beliefs about how physical activity and work affect pain were measured using the Fear-Avoidance Beliefs Questionnaire (FABQ) (Waddell et al., 1993). FABQ is a 16-item, two-factor self report questionnaire which has shown good psychometric properties. The items are answered on a verbal seven-point scale, ranging from 0 (strongly disagree) to 6 (strongly agree) and summed into a total score. The score ranges from 0-96, higher sums indicating stronger fear-avoidance beliefs. The original English version of FABQ has proved to be reliable and to have evidence for validity (Waddell et al., 1993). The Swedish version of FABQ has been widely used but there is no published evidence to support the validity of the Swedish version. A modified version of the FABQ (MFABQ) was found reliable on a Swedish pain population (Buer, 2003).

10.5. Fear Survey Schedule (FSS)

General fearfulness was measured using the Fear Survey Schedule (FSS-II) (Geer, 1965, Berggren et al., 1995). Akutagawa (1956) developed a Fear Schedule. This scale was elaborated on by Lang and Lazovik (1963) who called the scale the Fear Survey Schedule-II (FSS-II). Wolpe and Lang (1964) presented a fear scale called FSS-III. Geer (1965) performed a factor analysis and presented a version also called FSS-II or Geer Fear Scale. The original FSS-II comprises 51 questions and each item is rated on a seven point scale ranging from 1 (no fear) to 7 (terrified). The ratings are summed in to an index of general fearfulness. The higher the score the stronger the general fearfulness. The FSS-II has been tested for reliability and found to have enough evidence for validity in patients with dental fear (Berggren et al., 1995, Hakeberg et al., 1995).

10.6. Multidimensional Pain Inventory (MPI)

The psychosocial and behavioral consequences of pain were measured using the Swedish version of the Multidimensional Pain Inventory, MPI-S (Kerns et al., 1985, Bergström et al., 1998, Bergström et al., 1999). The MPI contains 47 questions ranging from 0 to 6 on a numerical rating scale, divided into different subscales, which are summarized into one psychosocial (part 1) and two behavioral (parts 2 and 3) sections. Section one (22 items) consists of five scales: Pain Severity, Interference, Perceived Life Control, Affective Distress, and Social support. Section two (12 items) consists of three subscales: Punishing Responses, Solicitous Responses and Distracting Responses. Section three (13 items) is summarized as general activity. Bergström et al. (1998, 1999) found MPI-S to be reliable and to have enough evidence for validity in a Swedish pain population.

10.7. Pain variables

The duration of pain was reported by the patient. Pain duration of less than six months was considered acute and pain duration of more than six months persistent. Pain localization was marked on a pain drawing and the number of localizations counted according to the classification of the International Association for the Study of Pain (IASP) (Merskey, 1979).

10.8. Physical exercise measures

Physical exercise (Study I) was measured using open questions constructed by the author (M.L.) about level, type and frequency of physical exercise. The questions about physical exercise concerned both current status and status prior to the onset of pain.

10.9. State and Trait Anxiety Inventory (STAI)

General anxiety was measured using the State and Trait Anxiety Inventory (STAI) (Spielberger et al., 1970) STAI assesses both state (STAI-S, temporary) and trait (STAI-T, more stable) levels of anxiety. Each STAI item ranges from 1 to 4, and includes inverted items. To obtain scores, the weighted scores of the 20 items that make up each scale are added together. The STAI has been widely used in clinical settings but no work has yet been published with reference to the reliability and validity of the Swedish version.

10.10. Visual Analogue Scale (VAS)

The pain intensity, at the time when completing the questionnaire was rated on a 100 mm visual analogue scale (VAS), ranging from “no pain” to “worst imaginable pain”(Scott and Huskisson, 1976).

11. The phenomenological-hermeneutic method

In order to answer the research questions and to capture the deeper understanding of the “experience of moving with pain” a qualitative research design was chosen. Qualitative research designs include many approaches such as content analysis, grounded theory, hermeneutics, phenomenography and phenomenology (Smith, 2003). For the purpose of this study a phenomenological-hermeneutic approach was chosen in order to deepen the understanding of the experience of moving with pain.

11.1. Phenomenology

Phenomenology today is not one but several philosophical, sociological and psychological theories. All phenomenological methods focus on the individual’s experience of a phenomenon and are based on phenomenological philosophy, which began with the work of German philosopher Edmund Husserl. Experience is intimately and indissolubly bound to the *life world* of the person, and it is in this context that any description must occur. The *lived world* (Husserl, 1936/1970) or the *life world* is a central theme in phenomenology. The lived world is the world in which we always live, together with others, and to which we may have a communicative relationship (Bengtsson, 1999). The distinction between the physical body and the *lived body* is even more important for the purpose of this thesis. Merleau-Ponty’s (1962) phenomenological philosophy is fundamental to our understanding of embodied knowledge because of his emphasis on *embodiment*. *Embodiment* is, expressed in simple language, how people know the world through their bodies (Wilde, 2003). Merleau-Ponty (1962) explored embodiment more fully in his phenomenological philosophy, and declared that one’s body was synonymous with existence. Expressed differently we do not *have* bodies, we *are* our bodies as body/subjects. The phenomenon under investigation here was *moving with persistent pain*.

11.2. Empirical Phenomenological Psychological (EPP) method

The Empirical Phenomenological Psychological (EPP) method (Karlsson, 1993) is a qualitative method analysis, which transcripts derived from in-

depths interviews, in a series of five analytic steps (Table 8). The findings are then presented in terms of either one general structure (if all the interviews exhibit the same meaning structure) or in “typologies” if a condensation of all protocols into one general structure would result in too abstract a structure. In empirical studies one may lose interesting discoveries if the results are presented in the most abstract (essential) form. Therefore results are often presented in typologies, where informative differences are maintained. Findings, which are general in that they can be applied to all the informants, are presented as general characteristics.

Table 8. The five steps of the Empirical Phenomenological Psychological (EPP) method (Karlsson, 1993).

	Name	Content
Step 1	Good grasp	The analysis has not yet begun. A <i>good grasp</i> is about getting a clear understanding of the content of the protocol. A normal understanding.
Step 2	Meaning units (MU)	The protocol is divided into smaller parts, called <i>meaning units</i> . The text is divided where there is a shift in meaning (and not in syntax)
Step 3	Eidetic induction	This is where the real analysis begins. The researcher uses <i>eidetic induction</i> through interpretation, which is the move from the particular fact to its psychological meaning. The purpose is to find the implicit and explicit meaning as the informant has experienced and described them in the protocol
Step 4	Situated structure	A <i>situated structure</i> is a synthesis of the different meaning units. This is where the researcher creates a phenomenologically meaningful structure of each interview.
Step 5	Final result: General structure Typology	The final result is a structure of the phenomenon. A <i>general structure</i> (many protocols of the same phenomenon) would arise if all interviews could be represented by one general structure. For empirical research it is often desirable to preserve interesting differences which results in so called “ <i>typological structures</i> ”.

12. Procedure

12.1. The procedure of Study I

The TSK-SV was tested according to the following procedure. First of all, consent from the original inventor of the TSK was obtained. The TSK was thereafter translated into Swedish by a bilingual psychologist and corrected by a professor in psychology. An authorised translator translated the TSK-SV back into English. The same scoring format and coding as in the original version of the TSK were retained. A pre-test was performed before the larger study was conducted. The purpose of the pre-test was to check the time required to respond to the instrument, to provide feedback on the items, to check whether or not the subjects understood the items and if they were reluctant to answer any of the questions.

The reliability test included stability over time, internal consistency and homogeneity. In order to test stability over time, a test-retest was performed. A letter was sent to the patients. Two weeks after the test questionnaire was received the retest questionnaire was sent. A reminder was sent to non-responders after two weeks. Two different methods were used to assess internal consistency. First, a Cronbach's alpha statistic (Cronbach, 1951) was calculated for the 17 items. Second, the item-total correlation was used to further explore the homogeneity of the scale.

The test of validity included face validity, content validity and construct validity. Translating the questionnaire back to the original language is one method of strengthening or confirming the face validity of the translated version. The panel of experts also assessed the face validity of the TSK-SV. Content validity was assessed by five physical therapists with extensive experience of working with patients with persistent pain and of analyzing content validity, who were asked to form an opinion of the content validity of the TSK-SV. Once the physical therapists had consented, information was sent to them along with the TSK-SV and a form to be completed on the subject of content validity. In order to collect evidence in support of construct validity two different methods were used: a factor analysis and the known groups' method. An exploratory factor analysis was conducted to investigate the factor structure of the 17-item TSK-SV.

Using the known groups' method, a criterion that can identify the presence or the absence of a particular characteristic is chosen. The most general type of evidence in support of construct validity is provided when a test can discriminate between individuals who are known to have a trait (in this study the trait is kinesiophobia) and those who are not. In order to analyze whether

or not the TSK was capable of discriminating between those who were expected to have a high degree and those who were expected to have a low degree of kinesiophobia, two groups were designed. The patient group consisted of patients expected to have a high degree of kinesiophobia, and the aerobics group consisted of subjects expected to have a low degree of kinesiophobia.

12.2. The procedure of Study II

The questionnaires (Table 7) were mailed to the patients prior to their first visit to the orthopaedic surgeon. The patients returned the completed questionnaires to an independent researcher.

An exploratory factor analysis was conducted to investigate the factor structure of the TSK-SV. For this analysis the extraction method based on maximum likelihood estimation was chosen. Convergent validity was evaluated between kinesiophobia (TSK-SV) and anxiety (STAI), disability (DRI), fear-avoidance beliefs (FABQ), general fearfulness (FSS), and pain intensity (VAS).

Due to the similarities between STAI and TSK in terms the theoretical framework (Kori et al., 1990, Asmundson et al., 2000, Vlaeyen and Linton, 2000), a close association between these two measures was hypothesized. An especially close association was expected between Factor III (Bodily anxiety) and STAI.

Based on our clinical experience and previous findings (Crombez et al., 1999, Swinkels-Meewisse et al., 2003, Roelofs et al., 2004, Woby et al., 2005) a close association between DRI and TSK-SV was hypothesized.

In accordance with previous results (Vlaeyen et al., 1995, Vlaeyen et al., 1995, Crombez et al., 1999, Roelofs et al., 2004), a close association between FSS and TSK was hypothesized. According to previous results of Vlaeyen et al. (1995) and in line with the theoretical framework, an especially close association between the TSK and the two subscales of the FSS-II “Fear of illness and death” and “Fear of physical injuries” were hypothesized.

Owing to the strong theoretical association (Lethem et al., 1983, Lilienfeld et al., 1993, Waddell et al., 1993, Vlaeyen et al., 1995), FABQ and TSK-SV should show a close association in practice. However, the FABQ physical subscale should be closely associated with TSK-SV, especially the factors which address fear of movement. The FABQ work subscale ought not to be closely associated with TSK since it addresses a different aspect of the fear-avoidance model.

From clinical experience, pain intensity is more closely associated with kinesiophobia in an acute state, as compared with a persistent state. Others have presented contradictory findings regarding the association TSK and VAS (Vlaeyen et al., 1995, Crombez et al., 1999, Swinkels-Meewisse et al., 2003).

12.3. The procedure of Study III

The questionnaires (Table 7) were mailed to the patients prior to their first visit to the physiotherapist. The patients returned the completed questionnaires to an independent researcher. The questionnaires included background data, pain variables, physical exercise measurement and psychological characteristics. All measures were self-reported.

12.4. The procedure of Study IV

In-depth interviews were performed at a place chosen by the patient. Only one patient chose to be interviewed at home, the rest were interviewed in a room at the physical therapy department. The interviews were tape recorded and lasted for 1-1.5 hours. All the interviews were performed by the same researcher (M.L.), who was also a physical therapist with long experience from rehabilitation of patients with persistent musculoskeletal pain. The interview questions were open-ended in order to stimulate detailed accounts of experience. The guiding question for the interviews was “How do you experience moving with your pain?” The researcher introduced the theme of “Fear” if the informants did not spontaneously do so. The interviews were transcribed verbatim and analyzed according to the EPP-method.

13. Statistical analyses

A word on statistics

*Out of a hundred people
those who always know better
-fifty-two*

*doubting every step
-nearly all the rest,*

*glad to lend a hand
if it doesn't take too long
-as high as forty-nine,*

*always good
because they can't be otherwise
-four, well maybe five,*

*able to admire without envy
-eighteen,*

*suffering illusions
induced by fleeting youth
-sixty, give or take a few,*

*not to be taken lightly
-forty and four,*

*living in constant fear
of someone or something
-seventy-seven,*

*unchanged.
capable of happiness
-twenty-something tops,*

*harmless singly, savage in crowds
-half at least,
cruel*

*when forced by circumstances
-better not to know
even ballpark figures,*

*wise after the fact
-just a couple more
than wise before it,*

*taking only things from life
-thirty
(I wish I were wrong),*

*hunched in pain,
no flashlight in the dark,
-eighty-three
sooner or later,
righteous
-thirty-five, which is a lot,*

*righteous
and understanding
-three,*

*worthy of compassion
-ninety-nine,*

*mortal
-a hundred out of a hundred.
Thus far this figure still remains*

Wisława Szymborska, 2002

*translated from the Polish language by
Joanna Trzeciak*

13.1. Data level

Statistical methods are specific to a certain type of data. Data can be either categorical or numerical (otherwise known as qualitative and quantitative) (Altman, 1991). The data level is a prerequisite to the choice of statistical method. The nature of the attribute being measured will determine the rules that can be applied to the measurement. Traditionally a mathematical structure defined by Stevens (1946) defines four levels of assigning numbers in measurement called scales of measurement. The four levels of measurements are called *nominal*, *ordinal*, *interval* and *ratio* (Figure 6).

Distance, age, time, weight, strength, blood pressure	Numbers represent units with equal intervals, measured from true zero	Ratio
Calendar years, IQ, degrees centigrade or Fahrenheit	Equal intervals between numbers, but not related to true zero; therefore, not representing absolute quantity	Interval
Manual muscle test, functional status, pain	Numbers indicate rank order of observations	Ordinal
Sex, nationality, blood type, clinical diagnosis	Numerals represent category labels only, classification	Nominal

Figure 8. The four levels of measurement according to Stevens (1946).

13.2. Choice of statistical methods

The choice of what statistical method to use is based on the data level as well as on how the variables are measured (operationalized). The statistical tests are based on assumptions about the parameters of the population from which the samples were drawn. The parametric tests require that the assumptions of normality and homogeneity of variance are met to a reasonable extent (Portney and Watkins, 2000). In Studies I-II the data derived from the questionnaires were treated as data on the interval level. In Study III data on the ordinal level (such as ratings from the questionnaires) were analyzed, taking the rank-invariant properties into account. Data on the ordinal level are evaluated by non-parametric tests. Non-parametric tests do not specify normality of variance assumptions (Portney and Watkins, 2000). An overview of the statistical methods used in this thesis is presented in Table 9.

Table 9. An overview of the statistical methods used in this thesis.

Methods	Study			Thesis
	I	II	III	
Descriptive statistics:				
Mean (SD)	•	•		
Median (min-max)		•	•	
Percentiles			•	
Differences between groups:				
Students' T-test	•		•	•
Mann Whitney U test			•	•
χ^2 test			•	•
Reliability:				
Intraclass Correlation Coefficient- two way mixed	•			
Pearson's product moment correlation	•			
Cronbach's alpha	•	•		
Standard Error of Measurement (SEM)				•
Validity:				
Explorative factor analysis	•	•		
Principal Component Analysis	•			
Maximum Likelihood		•		
Convergent validity				
Spearman's correlation coefficient		•		
Association:				
Correlation: Spearman's correlation coefficient		•		
Regression: Multiple logistic regression			•	

13.3. Data analysis

All data were computerized and analyzed using the Statistical Package for the Social Sciences (SPSS 10.0-13.0, Chicago IL). All reported confidence intervals (CI) were 95%. The significance level was set to 0.05.

13.3.1. Descriptive statistics

Descriptive statistics was used for the demographic data, which are presented as mean and standard deviation (Study I, II, III). Skewed values were presented as median and the minimum-maximum value. In Study III for data on the ordinal level (such as ratings from the questionnaires) the median value and the percentiles were used as descriptive measures.

13.3.2. Differences between groups

The differences between the two independent groups in Study I was tested with a Student's t-test.

The differences between two groups in Study III were tested with a Student's t-test for variables on the interval level and with Mann Whitney's U-test for variables on the ordinal level and with χ^2 test for variables on the nominal level.

The differences between differences between two groups (responders-non responders; men-women), in this thesis, were tested with a Student's t-test for variables on the interval level (age) and with Mann Whitney's U-test for variables on the ordinal level (TSK-SV) and with χ^2 test for variables on the nominal level (gender).

13.3.3. Reliability

The intraclass correlation coefficient (ICC), two-way mixed model, and the Pearson product-moment correlation coefficient were used for statistical analysis of the test-retest method. To assess the internal consistency a Cronbach's alpha coefficient was calculated (Cronbach, 1951), while the corrected item total correlation coefficient was used to assess the homogeneity of the TSK-SV. The reliability analysis was supplemented with the Standard Error of Measurement (SEM) for the purpose of this thesis.

13.3.4. Validity

The most common approach to construct validation is the use of factor analysis. Two different methods of factor analysis can be used to accomplish conceptual validation: exploratory and confirmatory factor analysis. Exploratory factor analysis (EFA) is used to find underlying dimensions of a conceptual domain, without a priori assumptions, through data reduction procedures. In contrast, confirmatory analysis is used to confirm a priori hypotheses (Floyd and Widaman, 1995). An explorative factor analysis (EFA) was used to assess construct validity. For the analysis in Study I the extraction method known as principal component analysis was employed, as it uses sums of the observed variables to optimally weight the maximal variability and reliability of the resultant factors (Gorsuch, 1983, Floyd and Widaman, 1995). For the purpose of Study I, the rotation method called Promax with Kaiser normalization was chosen. In Study II a maximum likelihood estimation with promax rotation with Kaiser normalization was used.

The Kaiser-Meyer-Olkin measure of sampling adequacy (KMO) was used to assess if the sample was appropriate for a factor analysis. There are

different criteria for the number of factors to extract (Nunnally and Bernstein, 1994, Hair, 1998, Kline, 2000, Thompson, 2004). In the Study I and II, three of the most well established criteria were used: the Kaiser-Guttman rule (Kaiser, 1960), the Scree-test (Cattell, 1966) and the percentage of variance criterion.

As a result of using the maximum likelihood estimation a goodness-of-fit test based on chi-square statistic was computed and used to test the adequacy of a factor model (Kline, 1994). Convergent validity was evaluated by computing Spearman correlation coefficients between kinesiophobia (TSK-SV) and anxiety (STAI), disability (DRI), fear-avoidance beliefs (FABQ), general fearfulness (FSS), and pain intensity (VAS).

13.3.5. Association, correlation and regression

Association incorporates prediction and agreement. Correlation is about assessing the association between two variables (Portney and Watkins, 2000). Regression is about predicting one variable from another (Altman, 1991). When the dependent variable is categorical the technique will be logistic regression.

The evaluation of the convergent validity was evaluated by computing Spearman correlation coefficients. For the purpose of these studies correlation coefficients between 0-0.25 is considered weak, 0.25-0.50 somewhat moderate, 0.50-0.75 moderate, and 0.75 and thereafter strong.

A simple logistic regression analysis was performed in Study III. The variables found to be significant in the simple analysis were subsequently analyzed in a multiple logistic regression model. Multiple logistic regression analyses were performed with dichotomized variables in order to obtain a multivariate perspective. Kinesiophobia was defined as a dependent variable. Pain variables, physical exercise measurements and psychological factors were independent variables. All variables were dichotomized according to the cut-off score described in the method section. When a cut-off score was not previously reported the median value from data obtained in this study was used.

13.4. Non-responders analyses

There was no difference between the responders (n=721) and the non-responders (n=573) regarding gender, χ^2 (1, N=1294) =0.04, p=0.11. The responders (M = 44.80, SD = 12.25) differed in age from the non-responders (M = 46.23, SD = 11.45), t (1294) = 2.08, p =0.04.

13.5. Missing value analysis

In this thesis all analyses are based on complete answers. There is a difference between missing and internal missing. Missing refers to a respondent who did not answer. Internal missing refers here to a single missing item in a completed questionnaire.

To be able to participate in Study III a minimum of 80% of all the questions in all the questionnaires must have been completed.

13.5.1. Missing value analyses of TSK-SV

The analyses of TSK-SV in this thesis are based on the complete answers as showed in Table 10. In Study I all incomplete TSK-SV questionnaires were excluded. In Study II missing values were excluded by pairwise deletion for the exploratory factor analysis.

Table 10. A distribution of the included patients in relation to internal missing and the complete TSK-SV.

Study	I	II					III	IV	Thesis
Subgroup	A	B	C	D	E	F	G	H*	
Request	214	112	138	293	140	28	369		1294
Included	119**	103	94	149	91	25	140		721
Internal missing	17	33	29	28	10	8	20		145
Complete TSK-SV	102	70	65	121	81	17	120		576

* *Not applicable to this kind of methodology*

** *The number included is different from Study I (n=102). In Study I all incomplete questionnaires (n=17) were excluded.*

The internal missing values (n=145) were evenly distributed between the 17 items of TSK-SV.

14. Ethical approval

All patients and subjects who participated in this thesis gave their informed consent. The studies within this thesis were approved by the Ethics Committee at the University of Göteborg (S-26300).

RESULTS

15. The psychometric properties of the Swedish language version of Tampa Scale for Kinesiophobia (Studies I and II)

15.1. Reliability

The ICC for the total sum of the TSK-SV was 0.91 (0.855-0.939). Pearson's product moment correlation coefficient for the total sum of the instrument was $r=0.91$, which was statistically significant ($p<0.001$) ($n=75$). Internal consistency assessed with Cronbach's alpha was 0.81 ($n=75$). The Standard Error of Measurement was 2.73.

15.2. Validity

The TSK-SV was considered to have face validity, meaning that the TSK-SV appeared to be measuring what is was intended to measure. The panel of experts was in overall agreement that the TSK-SV appeared to have content validity, and they considered the instrument relevant for the measurement of fear of movement. However, they generally found the items too numerous and some of the items too similar. The known groups' method showed a median value of 44 for the patient group, and 30 for the aerobics group (Figure 7). The difference between the groups was statistically significant ($p<0.001$).

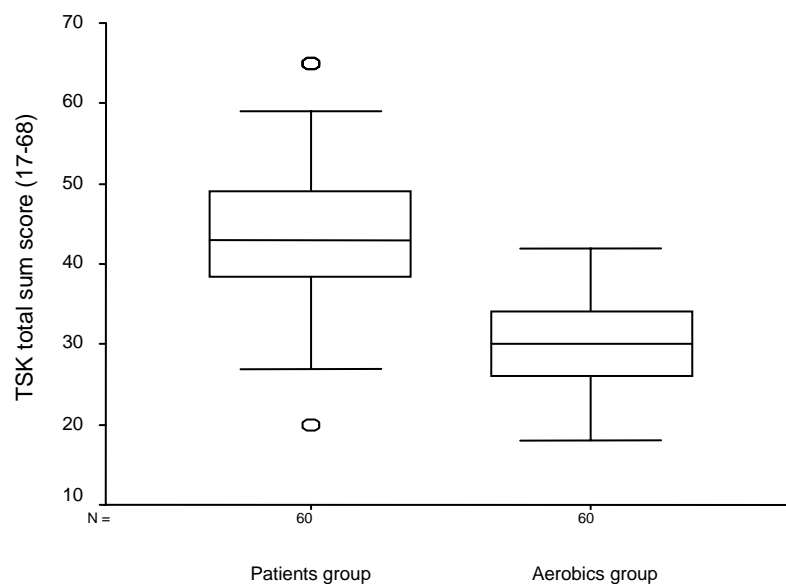


Figure 9. Box-plot presentation of the results from the known groups' method. The sum scores of the TSK-SV vary between 17 and 68 points.

Kaiser's (Kaiser-Meyer-Olkin measure of sampling adequacy) index was 0.74, indicating that the TSK-SV items were appropriate for principal component analysis. The factor analysis in Study I indicated a five-factor solution, which accounted for 59% of the variance. In Study II the Kaiser-Meyer-Olkin measure of sampling adequacy index was 0.83, indicating that the TSK-SV items were appropriate for a maximum likelihood analysis. The factor analysis indicated a five-factor solution, which accounted for 60% of the variance. The normed chi-square produced a ratio of 1.61 which indicated good support of the obtained five-factor model. The five factors designates as follows: Factor I, Fear of bodily harm, Factor II, Fear of movement/(re)injury, Factor III, Bodily anxiety; Factor IV, Importance of activity and Factor V, Avoidance of activity.

Table 11. The five-factor solution in Study II: Loadings and factor labels (Pattern matrix)

Item	Factor				
	I Fear of bodily harm	II Fear of (re)injury	III Bodily anxiety	IV Importance of activity	V Avoidance of activity
6	0.99	-0.05	-0.21	0.00	-0.18
5	0.68	-0.01	-0.04	-0.01	-0.14
3	0.42	0.01	0.37	-0.14	-0.03
7	0.33	-0.11	0.20	0.15	0.17
1	-0.10	1.04	0.02	-0.04	-0.10
9	0.03	0.80	-0.02	-0.05	-0.04
16	-0.10	0.02	0.84	0.01	-0.20
8	-0.12	-0.03	0.55	0.20	-0.12
11	0.12	0.05	0.54	-0.13	0.22
4	-0.15	-0.13	0.12	0.73	-0.02
12	0.15	0.01	0.17	0.57	-0.15
17	0.05	-0.01	-0.09	0.47	0.12
2	0.05	0.37	-0.12	0.45	0.07
13	-0.20	-0.12	-0.20	-0.02	0.79
10	0.25	0.08	-0.05	0.14	0.36
15	0.16	0.18	0.13	0.03	0.35
14	0.20	0.03	0.02	-0.02	0.24

16. The occurrence of kinesiophobia (Study I+II+III)

According to the operational definition in this thesis (TSK-SV>37) 70% of all the patients who participated in this thesis work showed a high degree of kinesiophobia. As shown in Figure 8, the occurrence of kinesiophobia varies among the subgroups.

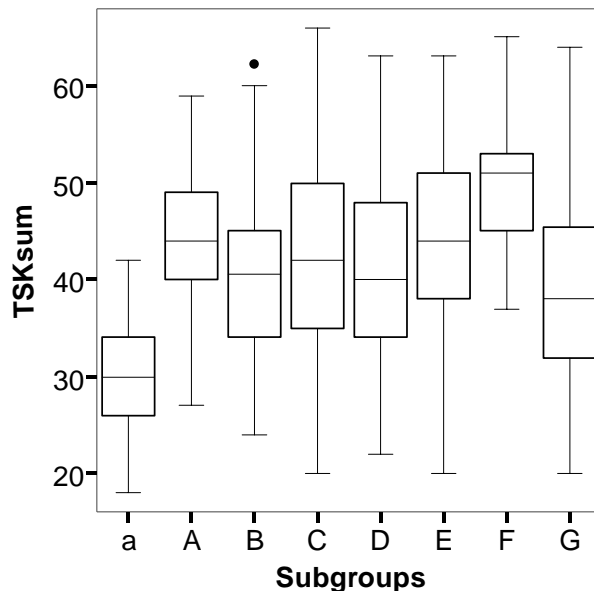


Figure 10. A description of the distribution of TSK-SV sum in the various subgroups. The sum scores of the TSK-SV vary between 17 and 68 points.

a=The aerobics group (*n*=60)

A=Persistent low back pain, orthopaedic outpatient clinic (*n*=102)

B=Persistent leg pain, orthopaedic outpatient clinic (*n*=70)

C=Heterogeneous persistent musculoskeletal pain, orthopaedic outpatient clinic (*n*=65)

D=Persistent low back pain, orthopaedic outpatient clinic (*n*=121)

E=Persistent low back pain (scheduled for surgery), orthopaedic outpatient clinic (*n*=81)

F=Heterogeneous persistent musculoskeletal pain (long term sick listed), orthopaedic outpatient clinic (*n*=17)

G=Heterogeneous musculoskeletal pain, primary health care (*n*=120)

16.1. Kinesiophobia in orthopaedic care

The majority of the patients (*n*=581) in this thesis were recruited from an orthopaedic setting. The percentiles for each of the subgroups are presented in Table 13. 70% of these patients scored >37 on the TSK-SV.

Table 12. The percentile values of The Tampa Scale for Kinesiophobia (TSK-SV) in the patients recruited from an orthopaedic setting. The aerobics group and the patients in Study IV are not included in this Table. The sum scores of the TSK-SV vary between 17 and 68 points.

Percentiles	B	C	A+D	E	F	Women	Men
Included patients	103	94	268	91	25	287	294
Complete TSK-SV	70	65	223	81	17	221	234
10	30	30	29	32	37	29	32
20	33	33	34	37	41	33	36
30	35	36	37	40	45	36	38
40	37	39	40	42	46	39	42
50	41	42	43	44	51	41	43
60	42	46	44	45	51	44	45
70	44	49	47	48	52	47	48
80	45	52	51	53	59	50	52
90	51	56	55	58	65	55	56

B=Persistent leg pain, orthopaedic outpatient clinic

C=Heterogeneous persistent musculoskeletal pain, orthopaedic outpatient clinic

A+D=Persistent low back pain, orthopaedic outpatient clinic

E=Persistent low back pain (scheduled for surgery), orthopaedic outpatient clinic

F=Heterogeneous persistent musculoskeletal pain (long term sick listed), orthopaedic outpatient clinic

16.2. Kinesiophobia in primary health care

In a pain population seeking care at two selected physiotherapy departments (Study III) 54% of the patients scored above >37 on the TSK-SV.

Table 13. The percentile values of The Tampa Scale for Kinesiophobia (TSK-SV) in the patients recruited from a primary health care. The sum scores of the TSK-SV vary between 17 and 68 points.

Percentiles	All patients N=140	Women n=97	Men n=43	Acute n=45*	Persistent n=79*
10	26	26	28	26	29
20	30	30	30	29	31
30	33	33	32	32	33
40	35	35	35	34	35
50	38	37	40	37	38
60	40	40	45	39	40
70	44	42	49	44	44
80	48	45	51	49	47
90	51	49	54	51	51

*16 patients failed to answer the question of pain duration.

17. Kinesiophobia and associated variables (Studies II+III)

In Study II the strongest correlation was found between DRI (physical disability) and kinesiophobia (TSK-SV). Factor III (Bodily anxiety) did not correlate significantly with DRI, suggesting that Factor III measures another dimension than DRI. A statistically significant correlation was found between STAI and TSK-SV for all the factors with the exception of Factor V. In the present study, there was no difference between STAI-trait and STAI-state in relation to TSK-SV. The lowest correlation was found between Factor V (Avoidance of activity) and STAI, indicating that anxiety and avoidance are not as closely associated as expected. In this study, Fear in general (FSS) correlated with the TSK-SV sum. No statistical correlation was found between subscales of the FSS-II “Fear of illness and death”, “Fear of physical injuries”. Fear-avoidance behaviour as measured by FABQ, showed a statistically significant correlation with the TSK-SV sum and FABQ physical subscale. As hypothesized no association between the FABQ work subscale and the TSK-SV and its subscales was found in the present study. Pain intensity turned out to be correlated with kinesiophobia for three of the five subscales.

Table 14. Spearman correlations coefficients between kinesiophobia (TSK-SV) and anxiety (STAI), physical disability (DRI), fear-avoidance beliefs (FABQ), general fearfulness (FSS-II), and pain intensity (VAS).

Variable	Factor I Fear of bodily harm 3,5,6,7	Factor II Fear of movement /(re)injury 1, 9	Factor III Bodily anxiety 8,11,16	Factor IV Importance of activity 2,4,12,17	Factor V Avoidance of activity 10,13,14,15	TSK Sum
STAI						
- state	0.55***	0.33*	0.55**	0.58**	0.28 ns	0.63***
- trait	0.56**	0.35*	0.48**	0.53**	0.28 ns	0.64***
DRI	0.69***	0.45***	0.29 ns	0.59***	0.51***	0.71***
FABQ						
- physical	0.25**	0.29**	0.20*	0.33**	0.33**	0.39**
- work	0.12 ns	0.09 ns	-0.04 ns	-0.04 ns	0.20 ns	0.12 ns
FSS-II						
-physical	0.15 ns	0.11 ns	0.11 ns	0.12 ns	0.12 ns	0.36**
-illness	0.12 ns	0.06 ns	0.07 ns	0.03 ns	0.16 ns	0.24*
VAS	0.09 ns	0.06 ns	0.01 ns	0.19 ns	0.10 ns	0.34**
	0.36**	0.25*	0.07 ns	0.34**	0.30*	0.41**

*p<0.05, **p<0.01, ***p<0.001

In Study III, factors that appeared to be associated with kinesiophobia according to the simple logistic regression analysis were; interference, disability, pain severity, pain intensity, life control, affective distress, depressed mood and solicitous response. Factors that did not appear to be associated with kinesiophobia according to the simple logistic regression analysis were; punishing responses, number of pain localisations, whether or not the patient engaged in physical activity (either currently or in the past), general activity, whether or not the patient had a diagnosis, social support, gender, distracting responses and duration of pain. The variables found to be statistically significant in the analysis of the raw odds ratios ($p < 0.05$) were analysed using a multiple logistic regression analysis. It should be noted that the BDI was not included, owing to the high incidence of internal missing values in that questionnaire.

Table 15. Summary of the simple regression analysis. "Internal missing" refers here to the missing values between TSK-SV and each variable. In the column Valid the numbers of patients in each analysis is presented (n=140). The variables are arranged by increasing p-values. Kinesiophobia is the dependent variable.

Variables	Measured by	Internal missing	Valid	Odds ratio	Confidence interval	p-value
Interference	MPI i	20	120	4.1	1.92-8.95	0.000
Disability	DRI	28	112	3.5	1.61-7.63	0.002
Pain severity	MPI ps	22	118	3.2	1.48-6.87	0.003
Pain intensity	VAS	26	114	2.7	1.27-5.79	0.010
Life control	MPI lc	21	119	0.4	0.19-0.87	0.020
Affective distress	MPI ad	20	120	2.3	1.08-4.76	0.030
Depression	BDI	55	85	2.5	1.05-6.09	0.039
Solicitous respons	MPI sr	29	111	2.2	1.03-4.79	0.042

18. Gender differences

More men than women in the observed population group (n=575) reported a TSK-SV value > 37 . There was a statistical significant difference between men (n=273) and women (n=302) regarding TSK-SV ($p=0.001$, Mann Whitney U). A similar difference between men (n=234) and women (n=221) regarding TSK-SV was found in the orthopaedic subgroups ($p=0.02$, Mann Whitney U). No such difference was, however, found between men (n=43) and women (n=97) regarding TSK-SV, in the primary health care subgroup ($p=0.318$, Mann Whitney U).

19. The meaning of moving for patients with persistent pain (Study IV)

No general structure was found that could take into account all the various meanings in the ten interviews. However, there was a general characteristic running through all the interviews which had to do with the experience that moving with persistent pain meant a dramatic change of their life-world. This dramatic change, showed itself in various phases as a process over time. This change over time included how the informants reacted to the changed terms of their life-world, how their identity altered in response to this change, and how they sought a new meaning in their new situation. The results of this study are presented in terms of three typologies, reflecting the different ways in which these informants experienced moving with persistent pain. The informants sometimes exhibited a characteristic from more than one typology, although each informant had a basic style or structure to his or her experience corresponding to one of the three typologies. The typologies are presented in detail below, and are referred to as *Failed adaptation*, *Identity Restoration* and *Finding the way out*.

Typology I: *Failed adaptation*

The experience of moving with pain was shocking and frustrating. It was difficult for these informants to accept that their lives had changed so radically. Limitations and obstacles were in focus and the psychological mood remained frustration and depressed mood, resulting in sleep deprivation and abuse of medications.

“When the pain was worst, I took painkillers and sleeping pills, and I also drank hard liquor to be able to sleep at night. Just to get through the night, really. I didn't care if I died, or what happened. That was how it was some days, because I was in so much pain.”
(Informant 4, page 6)

Passive coping strategies were chosen, such as lying down or avoiding movement. Out of fear of aggravating the pain, physical exercise such as biking, weightlifting and later even walking and standing were avoided.

”When I am in really bad pain one retreats and goes to bed...well...winds down completely. When it hurts real badly one doesn't do much that's for sure” (Informant 10, page 2)

The informants had physically demanding jobs and were physically active in their spare time. Their work and the physical exercise were previously important aspects of the meaning in the lives of these informants. A strong well-functioning body was an important source of identity, so this limitation of their ability to use their bodies led to a loss of identity. The lost identity was expressed as low self-esteem, bitterness and shame.

“I guess there is one side of me that hates the other side, which often gives me a sense of inferiority. When I think about myself I think I'm not really a complete person in comparison with others, since I can't work, and so on...” (Informant 10, page 9)

The feelings of low self-esteem, bitterness and shame were exacerbated by negative encounters from friends, peers and medical personnel. The medical encounters were experienced as repulsive and insulting.

“you get comments like you have just hurt your lazy-bones and that is the worst thing a person can hear when like me, you have a work you loved but could not handle. It is like a kick in the face” (Informant 4, page 5)

Finding a new structure and meaning in their new life was difficult, instead they mourned their pain free lives.

“I am a person who was always busy, I was never still, I was always on the road and I loved it. When I could not do it any longer I felt like a second-class citizen” (Informant 4, page 5)

Typology II: **Identity restoration**

At first, the experience of moving with pain was filled with fear, social isolation, depressed mood, negative self-esteem and shame. These informants were afraid of becoming dependent on pain killers, afraid of becoming wheelchair or afraid of losing their jobs. They described the social isolation as worse than the pain itself, and stated that the isolation gave rise to a sense of shame about not being able to be oneself. Isolation subsequently led to negative self-esteem and depressed mood.

“it makes you mental...it affects you mentally because you can't go along on anything. You get left behind. When the others took a walk I was left at home” (Informant 3, page 1)

The informants were grateful for the help they received, both from close relatives and health care professionals. However, before the right guidance was found, these informants experienced a time of chaos and abandonment. The initial contact with the health care system was described as a negative encounter. If they had had someone to talk to in the initial phase of pain, the phase of catastrophizing and fear could have been shortened, as well as the time spent in chaos, according to these informants.

“... then (when the pain starts again) it feels like some big nerve is being pinched, and I think, when it goes back to normal, I'll never be able to get out of bed. Lots of weird thoughts run through my head when I have such nasty pain. At times like that it would be good to have someone to talk to, someone who could say ... it's going to be all right.” (Informant 1, page 4)

The informants regained control of their lives by going through a process of reconsidering their existence and identity. A new identity was created based on the new reality they were facing. In order to create a new identity they applied their previously positive experiences of being physically active in coping with moving with pain. With guidance from physical therapists these informants achieved a certain amount of increased body awareness, which helped them to transform their way of being in the world of pain.

“There are doctors and everything and they are great and they say this and that, but you know your own body best. You have to listen to it. I have learnt to listen to it. I know my body completely. I have never been so aware...I know every little cracking in every joint, like you have never thought of before, but now you kind of learned to feel and listen.” (Informant 2, page 17)

These informants had some confidence in the future, although they all still had doubts. Despite these doubts, the informants had adapted to pain and begun their reorientation. This reorientation was described in terms of how their previous life had been re-evaluated and they had reconsidered their definition of quality of life.

“So there I was standing at the kitchen table eating my breakfast and that is one of those things that really gets you damned upset, having to start the day like that, but now I do not have to anymore. I

can sit down and light a candle, I can get my paper and I can eat my breakfast sitting in peace and quiet. The day starts better then. You get a more pleasant feeling in your body.” (Informant 1, page 16)

Typology III: *Finding the way out*

The informants in this typology managed to get through the crisis of experiencing moving with pain. The acute phase of pain was filled with depressed mood, anxiety and pain attacks. They had difficulties in giving themselves the time and patience to be able to move on. After a relatively short while they accepted their changed life conditions, which enabled them to get on with their lives.

“I quite simply have to restrict my activities. In any case, I can't get around as much as I guess most people can. I'll never be able to ski downhill again, though I can manage fine on my cross-country skis on the lake, where it's flat. That's great.”
(Informant 5, page 1)

Factors such as a positive encounter with health care personnel and support from their closest friends and relatives were considered helpful in the rehabilitation process. Well-functioning active coping strategies were already used, such as physical exercise, socializing with friends or working in the garden. All but one person in this group had a previously positive attitude towards physical exercise. That informant learned to enjoy physical exercise during her period of pain.

“... one of the things that keeps my mood brighter is actually the exercise, because I keep doing it and keep at it and when I leave here (the physiotherapy department) I feel better, both mentally and physically. When I leave, for instance, I can feel that it's easier to walk, that I'm less tense, so I know that the exercise makes me feel better. It strengthens my whole self.” (Informant 7, page 1)

All the informants in this group expressed thoughts about how the balance between body and mind was altered as a consequence of pain. Previously they had taken their bodies for granted and paid no attention to them. The pain forced them to think about their bodies and in doing so their existence and

identity came into focus. Thoughts about body and mind were more clearly expressed here than in the other typologies.

“What I learned, sort of, was that it's not my will power or my mind that is making me have the pain. I was kind of able to sift that out, in order to realize that I will have to get on with things, by myself, in spite of the pain. And what I had to do was to distinguish between my self and my body. My body baulks, but I want to go on, and I think that has made me even more aware that I have to stop taking my body into account. I have to set it aside and get on with things as I am. So now they (mind and body) make more sense to me.” (Informant 6, page 8)

Through their experiences of pain these informants learned new things about themselves. They developed empathetic abilities and gained patience both with themselves and with others. The informants experienced the vitality of life and saw the good in life despite difficulties and persistent pain. They also described an inner drive, which helped them find the way out.

“I think that everybody has it within themselves, that they would like to find ways out so that...If it does not work one way there is another way to go. Now it's working, I am getting better all the time since I found the ways out.” (Informant 9, page 10)

GENERAL DISCUSSION

20. The Swedish version of the Tampa Scale for Kinesiophobia

Since we decided to use an already existing questionnaire, the TSK, the main methodological consideration, closely linked to statistical considerations, was what methodology to choose in order to evaluate the quality of the instrument. After careful consideration we chose to evaluate according to the psychometric theory. Rating scales have been used in psychology for over 100 years and are widely used to measure qualitative variables in other disciplines. There is a tradition in psychology to use a parametric approach for analyses of rating scales (Cronbach, 1990, Spector, 1992). According to the psychometric tradition, parametric tests are generally considered robust and able to withstand even major violations of the assumptions of underlying parametric statistics, without seriously affecting the validity of statistical outcomes (Nunnally and Bernstein, 1994, Portney and Watkins, 2000).

Different types of reliability data require different statistical tests, but there is a lack of consensus as to which tests are most appropriate (Atkinson and Nevill, 1998, Rankin and Stokes, 1998, Holmbäck, 2002). Even within the psychometric tradition there is no consensus as to what should be included in an analysis of reliability and validity. Good psychometrics testing, according to Kline (1998), includes high reliability, high test-retest consistency and high internal consistency (0.70 is a minimum figure) low standard error of measurement, and good evidence of validity, especially construct validity and high discriminatory power.

Based on the findings of this thesis, we conclude that TSK-SV is reliable. The ICC calculated in Study I was 0.91 for the sum of the total score. Fleiss (1999) concluded that ICC values above 0.75 represent excellent reliability and values between 0.40 and 0.75 represent fair to good reliability. However, Atkinson and Nevill (1998) stated that no clear definition of acceptable ICC points for practical use has yet been presented. The ICC reflects both degree of correspondence and agreement among ratings and is recommended as a single index to describe reliability (Portney and Watkins, 2000). The ICC has been presented as more advantageous than Pearson's product moment correlation coefficient since it accounts for the actual magnitude of score and the agreement between ratings, not only the correlation and linear association among variables (Bergström et al., 1998, Portney and Watkins, 2000). The ICC assesses the proximity of the points to a particular line, whereas Pearson's correlation coefficient assesses the proximity to any straight line. In

the present study both the ICC and Pearson's product moment correlation coefficient were presented. The reason for doing so was to be able to compare our results with those of Swinkels-Meewisse et al. (2003).

The Pearson's product moment correlation coefficient in the present study was 0.91, which can be considered good. In the existing literature pertaining to TSK Swinkels-Meewisse et al. (2003) and Woby et al. (2005) address the issue of stability over time. Swinkels-Meewisse et al. (2003) presented a Pearson's product moment correlation coefficient of 0.78 for the complete TSK version, using a time interval of 24 hours. Woby et al. (2005) presented an ICC of 0.82. For research purposes, reliability coefficients of $r=0.70$ are sufficient. If important decisions are made with respect to specific test scores, a reliability of 0.90 is the bare minimum, and a reliability of 0.95 for applied settings should be considered a desired standard. It must be stressed that a reliability coefficient has a numerical meaning only in respect of a specified population (Nunnally and Bernstein, 1994). The difference between agreement and correlation is important. A high correlation does not mean that the two measurements (in this case test-retest) agree (Bland and Altman, 1986).

The standard deviation of the measurement error reflects the reliability of response and provides an indication of the error associated with a measure in the same units as that measure. This standard deviation is the Standard Error of Measurement (SEM). In the present study a SEM of 2.73 was presented. According to these values, a change of at least three points on the TSK-SV is required to be considered a change in patient's kinesiophobia. Woby et al. (2005) presented a SEM of 3.16 for the TSK total score.

The Cronbach's alpha value in the present study was 0.81, which is fair. Figures in the range of 0.70-0.90 are preferable even if values as low as 0.60 may be acceptable (Theorell et al., 1993). This can be compared to the 0.77 presented by Vlaeyen et al. (1995). It is also slightly higher than 0.68-0.80 found by Crombez et al. (1999). Swinkels-Meewisse et al. (2003) reported alpha values between 0.70 and 0.80, which are considered to be satisfactory when group scores are being compared (Bland and Altman, 1997). Roelofs et al. (2004) presented an alpha value of 0.81 for patients with persistent low back pain and 0.79 for patients with fibromyalgia. Goubert et al. (2004) only presented alpha values for a shortened version of the TSK. The limitation of the Cronbach's alpha value is that it is related to number of items. So, by simply adding more items the alpha value increases (Kline, 2000). A too high value (>0.95) indicates that the items are too closely related. Criticism of Chronbach's alpha includes that it is based on an assumption of normality

which, according to Svensson (2001), is seldom observed in data from rating scales.

In the present study corrected the item-total correlation coefficient was used to assess the homogeneity of the scale. Woby et al. (2005) were the only ones of the authors of the existing literature on the psychometric properties of the TSK that addressed this issue. A coefficient of around 0.40 is considered desirable (Spector, 1992, Sullivan et al., 1993), and indicates that items in the questionnaire measure different aspects of the same construct. Woby et al. (2005) stated that a coefficient of less than 0.20 (Streiner and Norman, 1995) are likely to be assessing a different construct from the other items on that measure. The Study I results indicate that not all of the items measure a unique aspect of the construct. This also supports the opinion of the panel of experts, who suggested that the items were too many and too similar.

The validity of an instrument is extremely difficult to establish (Kline, 1998) and no questionnaire can be considered to be perfectly valid (Kline, 2000). Whether or not a test is valid, is ultimately a matter of opinion in the light of the evidence about its validity (Kline, 1998). Validity is thus about collecting evidence.

The TSK-SV was considered to have face validity, meaning that the TSK-SV appeared to measure what it was intended to measure. In more accurate terms, evidence was found to support the face validity. Guilford (1959) argued that face validity in personality tests was actually bad for true validity since it caused subjects to distort their results according to how they liked to appear on the variable. Kline (1998) stated that there is no logical relationship between face validity and real validity. In some conditions there may be a positive correlation between them, whereas in other circumstances, such as selection, face validity may be a real disadvantage (Cattell and Warburton, 1967, Kline, 2000).

The panel of experts was in overall agreement that the TSK-SV appeared to have content validity, and they considered the instrument relevant for the measurement of fear of movement. An instrument is said to have content validity if it covers all parts of the universe of content and reflects the relative importance of each part (Nunnally and Bernstein, 1994). The determination of content validity is essentially a subjective process (Portney and Watkins, 2000), and there are no statistical indices to assess content validity.

The known groups' method revealed a statistically significant difference between the two groups (patients and aerobics groups), which supports the evidence of TSK's construct validity. Our hypothesis, that there should be a difference between these groups, was based on the notion that in relation to

kinesiophobia, the aerobics group chose to be physically active although they had pain. The patient group was hypothesized as not having come as far in their rehabilitation process. Also, in the known groups' method there are no clear rules as to what evaluation methods to use.

An EFA was conducted to investigate the factor structure of the TSK-SV (Study I). The aim of Study I was to take a first step in evaluating its basic psychometric properties. KMO index in Study I was 0.74, and in Study II 0.83, indicating that the TSK-SV items were appropriate for factor analysis. A value of 0.80 is desired (Hair, 1998).

The three criteria (Kaiser-Guttman, Scree test and the percentage of variance), together with the stricter normed chi-square criteria, provide evidence for a five-factor model. According to the Kaiser Guttman rule, only factors that have latent roots or eigenvalues greater than 1.0 should be included in the factor model. In both studies (Studies I and II) five factors had eigenvalues greater than 1.0. The Scree test complements the Kaiser-Guttman rule. It essentially looks for a marked break between the initial main factors that explain the largest proportion of the variance and the late smaller factors that explain very similar and small proportions of the variance (Cramer, 2003). The factor analysis in Study I indicated a five-factor solution, which accounted for 59% of the variance. In Study II 60% of the variance was explained by the five-factor solution. There is no absolute threshold for the percentage of variance. In the social sciences, 60% of the total variance is considered satisfactory (Cramer, 2003).

As a result of using the maximum likelihood estimation, a goodness-of-fit test based on chi-square statistics was computed (Study II) and used to test the adequacy of a factor model (Kline, 1994). A significant chi-square statistic ($p < 0.05$) indicates that the factor model does not provide a very good prediction of the observed correlations. However, a weak part of this test is its dependence on sample size. A large sample size would estimate a very small difference, associated with small practical relevance, as a significant deviation between the observed and the predicted model. Thus, since this test is sensitive to sample size, it is preferable to use the normed chi-square, which is the chi-square value divided by the degrees of freedom. A recommended ratio for good fit is about 2-3, while a value less than 5 has been suggested as an acceptable fit (Kline, 1994).

The EFA in Study II was performed on a relatively large sample ($n=494$). To achieve statistically reliable results, factor analysis should not be performed on fewer than 200-300 subjects (Gorsuch, 1983, Tabachnick and Fidell, 2000). Factor analyses on TSK have been performed on fewer than

200 subjects (Vlaeyen et al., 1995, Clark et al., 1996, Geisser et al., 2000, Carter-Sand et al., 2004, Lundberg et al., 2004). Any changes in a questionnaire should be supported by a considerable amount of data. Unfortunately, alterations of the TSK have been performed based on small samples, which have resulted in difficulties in comparing and thus generalizing from the results. The number of subjects is, however, not crucial to the clinical interpretation. Researchers must be cautious about how “factors” are interpreted, as they are not real measurement entities, but only hypothetical statistical concepts (Nunnally and Bernstein, 1994). The EFA performed in Study II presented a five-factor solution which, together with the subsequent test of construct validity, provided evidence for the multidimensionality of TSK.

The question may arise as to why an exploratory factor analysis (EFA) was performed in Study II when there are already so many existing factor models of the TSK. First and foremost, a measure is valid only in relations to the conditions it has been tested for (Nunnally and Bernstein, 1994). Secondly, it was desirable to investigate the dimensionality of the TSK-SV on a large sample in an orthopaedic setting. For this purpose, the EFA is the analysis of choice. Finally, there is not one distinguished factor model that can be replicated. Ten various factor models of the Tampa Scale for Kinesiophobia (Miller et al., 1991, Vlaeyen et al., 1995, Clark et al., 1996, Cohen et al., 2003, Gironde et al., 2003, Goubert et al., 2004, Lundberg et al., 2004, Burwinkle et al., 2005, Woby et al., 2005, Swinkels-Meewisse et al., 2006) found. The different factor models use different sets of items to describe different concepts.

Methodological differences and the fact that only four (3, 6, 7, 11) of the 17 items were included in other models made comparisons difficult. However, the 5-factor solution in Study II showed close similarities to the 4-factor solution reported by Vlaeyen et al. (1995), although they excluded items 5, 7, 8, 16 and 17. Nine of their remaining 12 items fell into the same factors as in the present study. Our five-factor model also showed a close relationship with the 6-factor solution presented by Burwinkle et al. (2005), although items 2, 14 and 17 were excluded because they loaded on more than one factor.

Some researchers have argued that there is really only one form of validity, construct validity (Nunnally and Bernstein, 1994, Kline, 1998). There are three major aspects of construct validation: specifying the domain of observables related to the construct, determining the extent to which observables tend to measure the same thing, and performing subsequent

individual differences studies and/or experiments to determine the extent to which supposed measures of the constructs are consistent with “best guesses” about the construct. Nunnally and Bernstein (1994) stated that researchers have a tendency to develop a measure of a construct and then leap to the third aspect, e.g. correlating a particular measure of anxiety with a particular measure of shyness. Instead of tightly defining the initial domain of observables for the construct, the nature of the domain is usually suggested by numerous attempts to develop particular measures of the construct. I would argue that this is the case with TSK. Kinesiophobia was not tightly defined within a theoretical framework from the outset, as showed in the multidimensionality of TSK.

There are other methods than the psychometric method to evaluate reliability and validity. As opposed to psychometric theory, that assumes that data are normally distributed and treated as data on at least interval level, others argue that data from questionnaires are ordinal data (Agresti, 1990, Svensson, 1998). According to Svensson (1993) the lack of additivity of ordinal data demands non-parametric rank-invariant statistical methods. The main property of ordered categorical data is that the categories represent a rank order according to the amount or intensity of that particular concept. As distances between the scale categories are indeterminate, the categorical labels do not represent any mathematical value but only an order, therefore, arithmetics cannot be applied to ordered categorical data (Feinstein et al., 1986, Merbitz et al., 1989, Coste et al., 1995, Sonn and Svensson, 1997). Svensson (1993) has developed a family of non-parametric rank-invariant methods that are valid for all types of ordered data without assumptions about the distributions. Bunketorp et al. (2005) applied Svensson’s method to evaluate the reliability of a slightly different version of TSK-SV, and found it reliable. Similar results have been found by Lundberg (2002).

Another model available for evaluation of measurement quality is the Rasch Model (Rasch, 1960), or actually the Rasch models (Andrich, 1988, Fisher, 1993). The Rasch models are logistic models in item response theory, in which a person’s level on a latent trait and the various items on the same latent variable can be estimated independently (Acton, 2003). The Rasch models are based on the idea that data must conform to some reasonable hierarchy of “less than/more than” on a single continuum of interest. The model asserts that the easier the item, the more likely it will be affirmed. Meaning that the more able the person, the more likely he or she will affirm an item compared with a less able person (Gilworth et al., 2003). This model

can help to transform raw data from the human sciences into abstract, equal-interval scales (Bond and Fox, 2001).

In summary, TSK-SV has proven to have high reliability, high test-retest consistency and high internal consistency, low standard error of measurement, and good evidence of validity. Problems associated with TSK-SV are related to the lack of a specified domain of the construct kinesiophobia.

21. The occurrence of kinesiophobia

Interestingly, 70% of all the patients in Studies I, II and III who sought care because of musculoskeletal pain showed a high degree of kinesiophobia (defined as >37 on TSK-SV). In the orthopaedic groups (Subgroup A, B, C, D, E and F) 70% of the patients also showed a high degree of kinesiophobia. There were variations among the subgroups and between the sexes. Subgroup F differed most from the other groups. In subgroup F the median value was 51 as compared to 41 in subgroup B. Subgroup B included patients with persistent leg pain due to exercise, whereas subgroup F included patients who were referred to the orthopaedic clinic from the social insurance office for an evaluation of their remaining work capacity.

Within the orthopaedic subgroups further sub-grouping would be of interest. For instance, it would be of interest to know what the relation to kinesiophobia is, depending on whether the patient has an unspecific low back pain diagnosis (such as lumbago), or a specific low back pain diagnosis (such as spondylolisthesis). It would be more interesting to penetrate how the diagnosis was brought to the patient and what the messages were in relation to restrictions and recommendations of physical activity. That is, however, another story, to be continued in subsequent studies.

The limitations of the estimates of the occurrence of kinesiophobia are related to what operational definition is used. There is no consistent operational definition of kinesiophobia. When can a person be considered *kinesiophobic*? As mentioned before kinesiophobia is a construct rather than being a disease or other pathological state in and of themselves (McNeil and Wovles, 2004). Like depression or any other psychological construct one cannot tell from observation, but must rely on a thorough psychological assessment in order to diagnose the condition. Self-reported measures, can also be used, often with cut-off values to classify a condition. The measure linked to kinesiophobia is the TSK. Kori et al. (1990) who first described the phenomenon, and later designed the TSK (Miller et al., 1991), did not give any exact guidelines. They said “patients scoring high on the TSK can be considered kinesiophobic sufferers”.

A variety of different means and medians have been presented as reference values, of which the minimum was 35 and the maximum 42.3 (Reneman et al., 2003, Boersma et al., 2004, de Jong et al., 2005). For the purpose of Study III we used a cut-off score >37 , i.e. the original operational definition presented by Vlaeyen et al. (1995). The use of this value was supported in Study I. Boersma et al. (2004) used a cut-off score of >35 . If we had used this value, 75% of the patients would have presented a high degree of kinesiophobia. Although there are problems associated with the use of cut-off values, we wanted to use the original operational definition in order to make our results comparable. In our opinion, the problem of operationalizing kinesiophobia boils down to the absence of a consistent conceptual definition of kinesiophobia.

What are the consequences of not having a consistent conceptual and operational definition? When you want to use a questionnaire to evaluate a rehabilitation outcome, you have to have clearly defined cut-off values in advance. Otherwise there might be problem interpreting the results. Linton et al. (2002) experienced that their patients decreased their fear-avoidance beliefs, but it was not shown on the TSK. The patients continued to have high scores even after successfully participating in the treatment. This may reflect a problem with the questionnaire or it may reflect a smaller improvement than noted in the original study. Depending upon the operational definition used, the occurrence of kinesiophobia will vary.

This thesis provides information about a heterogeneous pain population, recruited from an orthopaedic and a primary health care setting. So far, most of the research regarding kinesiophobia and related concepts has been applied to patients with persistent low back pain in a pain clinic setting. Buer (2003) found that higher fear-avoidance beliefs in patients with fractures increased the risk of having pain at follow-up and not having full muscle strength. In Study III, 54% of the patients who sought care at a physiotherapy department in primary health care presented a high degree of kinesiophobia. These studies do not claim to be epidemiological studies but can give an indication that pain-related fears are an issue even in orthopaedic care and primary health care. Buer and Linton (2002) demonstrated that fear-avoidance beliefs do occur among the general population of people without pain problems, and moreover, that such beliefs increase the risk by twofold of a future episode of spinal pain.

High levels of fear of movement/(re)injury have been found in several patient groups such as patients with fractures (Buer, 2003), fibromyalgia (de Gier et al., 2003), complex regional syndrome (de Jong et al., 2005),

rheumatoid arthritis (Lundgren, 2005), and in patients with anterior cruciate ligament injuries (Kvist et al., 2005). This is also a particularly important quality of life aspect for patients with cardiovascular disease, who often have anxiety, depression and deceptive health beliefs (Lewin et al., 2001). There are difficulties in comparing the results since various measures are used to analyze vaguely described constructs.

In summary, the occurrence of kinesiophobia was high (70%) among the patients with musculoskeletal pain. There is, however, a lack of a consistent operational definition of kinesiophobia, or pain-related fear or fear of movement, which influence the possibility of estimating the occurrence and to compare results.

22. Kinesiophobia and associated variables

Based on our prior knowledge, clinical experience and previous research we wanted to test certain selected variables and their association with kinesiophobia.

The strongest correlation between DRI and TSK-SV were found in Factor I (0.69, $p < 0.001$) and in the use of the total score (0.71, $p < 0.001$). Disability was found to be associated with kinesiophobia, even in Study III. Applied to the correlations above, the explained percentage of variance would be 48% (0.69^2) – 50% (0.71^2). The interpretation of correlations should preferably be analysed together with the percentage of the variability of the data (Altman, 1991). It is also important to interpret the results on a theoretical and clinical basis.

A statistically significant correlation was found between STAI and TSK-SV in all five factors. These findings correspond well with anxiety as the primary affective component of phobias (Beck et al., 1985). A statistically significant correlation between STAI-state and TSK-DV has previously been reported (Vlaeyen et al., 1995), whereas no statistical association was found between STAI-trait and TSK-DV. There is an association between kinesiophobia (TSK) and general anxiety (STAI), but it needs to be elaborated further. These are interesting findings related to the theoretical models of negative emotionality (Lilienfeld et al., 1993), negative affectivity (Watson et al., 1988, Asmundson et al., 2000) and health related anxiety (Asmundson et al., 2001).

Fear in general (FSS) correlated with the total score of TSK-SV. These results are similar to those presented by Vlaeyen et al. (1995), who found a correlation of 0.32 ($p < 0.001$) between Fear of bodily injury (FSS-III-R) and TSK-DV. Other authors have correlated various measures of fear against TSK

and found statistical correlations (Crombez et al., 1999, Roelofs et al., 2004). Study II showed a stronger correlation between general anxiety and kinesiophobia than between general fear and kinesiophobia. These results indicate a closer relationship in theory between kinesiophobia and anxiety than between kinesiophobia and fear.

FABQ showed a statistically significant correlation with the total score of TSK-SV. The correlations only explained 4%-15% of the variance. FABQ ought to be closely associated, owing to the strong association in theory (Lethem et al., 1983, Lilienfeld et al., 1993, Waddell et al., 1993, Vlaeyen et al., 1995). The lack of strong correlation between FABQ and TSK-SV might be because the domains related to the questionnaires are not specified in enough detail.

VAS correlated more strongly with TSK-SV than has been shown in other studies (Vlaeyen et al., 1995, Crombez et al., 1999, Swinkels-Meewisse et al., 2003). This might be a result of our sample being derived from a more heterogeneous pain population than in the other studies. Even so, in our study, the correlations between TSK-SV and VAS were only somewhat moderate. A moderate correlation was previously found between kinesiophobia and pain intensity in a low back pain population (Nederhand et al., 2004). Swinkels-Meewisse et al. (2003) showed that pain intensity predicts disability in patients with acute low back pain, where disability also plays a mediating role in the association between pain intensity and kinesiophobia.

According to our findings from the simple logistic regression interference, disability, pain severity, pain intensity, life control, affective distress, depressed mood and solicitous responses seemed to be associated with kinesiophobia. It is of importance to stress that a cross-sectional design does not enable prediction. However, none of the factors included in the multiple logistic regression was statistically significant. Using logistic regression analysis, we dichotomized all variables, which made the analysis coarser than if we could have divided the variables in a more fine tuned analysis. Another reason might be that the factors included were too similar, meaning that the factors were too strongly correlated. Finally, we might have had too little data to detect a significant difference. The higher number of internal missing in the multiple logistic regression model as compared with the simple logistic regression analysis is due to the fact that only data with valid values for each variable were included in the multiple analyses.

Several factors in Study III did not turn out to be associated with kinesiophobia. One of those factors was physical exercise. At the time when we constructed our questions we did not find a suitable reliable and valid

measurement for physical exercise, which answered our questions. We preferred open questions in order to collect data as close to the patient's truth as possible. One limitation of this design was that physical exercise was not defined clearly enough for the patients. In a layman there is not necessarily a difference in meaning between physical exercise and physical activity. One options today to measure physical activity, would be the International Physical Activity Questionnaire (IPAQ) (Craig et al., 2003).

It is important to realize that disuse, as described in the physiological literature, is referred to in a context of immobility, whereas in persistent pain disuse is referred to as in a state of inactivity (Verbunt et al., 2003). For patients with a formerly active lifestyle, both a perceived decline in the level of physical activity and the actual level of physical activity seemed more disabling than for patients with a formerly sedentary lifestyle (Verbunt et al., 2005). This was shown in one of our subgroups (Subgroup B) who all were athletes and scored high on TSK-SV but low on other psychological measures (Karlsson and Styf, SOF). For the patients with a formerly sedentary lifestyle, factors such as depression and pain intensity appeared to be more disabling (Verbunt et al., 2005). In our subgroup (Subgroup F), with a more sedentary lifestyle, the patients scored higher on all psychological measures, not only TSK-SV. So far, little attention has been paid to movement component in fear-avoidance models. This is also reflected in the items of TSK where there is a mixture of physical activity, physical exercise and movement. There is a need for clearer and more stringent definitions of movement, physical activity and physical exercise in relation to pain-related fear.

One hypothesis I had from outset of this thesis was that whether or not the patient had a confirmed diagnosis or not would have an impact on the subjective experience of kinesiophobia. This was tested in Study III, on patients with musculoskeletal pain in a primary healthcare setting, and we found no such association. This is interesting from that point of view that from a biomedical perspective there is a strong focus on diagnosing. In Study IV we found that the most important thing for the informants was to be taken seriously and to experience a positive medical encounter. This tells us that it is not the diagnosis as such but the meaning that is attributed to it that is important. This is not to say that a detailed examination is not useful. However, it needs to be supplemented with time to the patient and his/hers beliefs and cognitions. It would be interesting to further penetrate whether or not the patient had a specific or unspecific diagnosis of low back pain had an impact of kinesiophobia.

In summary, kinesiophobia correlated moderately with disability and anxiety. In relation to our results kinesiophobia seems more strongly associated with anxiety, and disability than to fear.

23. The meaning of moving with persistent pain

The phenomenon moving with persistent musculoskeletal pain has not previously been investigated, so Study IV provides unique findings. The principal finding was that “*to move with persistent pain*” implies much more than the physical movement itself, as moving in everyday life is existing in the world. When analysing qualitative data we can no longer talk about causal relations and explanations in the strict scientific sense. Meaning is not analysable in the scientific terms of causal explanation.

The fact that movement can not be separated from life was clearly expressed by all informants in study IV, supporting the need for the perspective of the *lived body* in health care research. Although they might not be aware of the term the lived body, the informants expressed in their own words how the world appeared through their aching bodies. These results are interesting from a phenomenological philosophical perspective, since they indicate an implicit understanding of the lived body. The body, understood in this way, as the foundation of existence, is the lived body. The lived body is the embodied subjectivity of the person in his/her concrete life situation (Merleau-Ponty, 1962, Bullington, 1999). The informants in the present study clearly stated that to move with persistent pain meant a dramatic change in their lives. This dramatic change, showed itself as a process over time, with implications on several aspects of life.

All informants in Study IV related their experiences of moving with persistent pain to a process in time. They described how they experienced the transition from acute to persistent pain. Time as a phenomenon in patients with was analyzed in depth by Hellström (1998), who found disorganization in subjective time, i.e. a disturbed temporal orientation in the pain situation. A disorganization regarding subjective time was described by all informants in the present study. The informants in typology I (Failed adaptation) became stuck in their pain and were not able to reorganize their lives and see the future. This phenomenon was described by Hellström and Carlsson (1996) as *Frozen futures*. Futures that were once expected, planned for, desired, hoped for, or feared, were now impossible, but still existed as thought alternatives to the future now perceived as realistic. The informants in typology II (Identity restoration) and III (Finding the way out) were more orientated towards a future, and managed to reorganize and get on with their lives. Persistent pain

has been found to interfere with a person's current task, plans and goals and to cause a "biographical disruption" (Bury, 1988) that changes the person's perspective of him or herself both with respect to the past and the future. This challenges and threatens the person's sense of self, and requires a response to accommodate or assimilate the challenge (Schmitz et al., 1996).

The bodily change meant a changed identity. Our bodies are central in our lives, and when the bodily prerequisites change, the meaning of life changes as well. For the informants in typology I, for whom a strong body was their main identity, we could see the most dramatic experience of the bodily changes caused by pain. This is interesting to reflect upon in relation to the lifestyle of the person who presents with pain. The loss of identity was described in terms of shame, loss of selfrespect and loss of meaning. The informants in the two other typologies, who had other identities as well, such as a rich social life or interests such as gardening, did not experience the bodily change as dramatically.

Other authors speak of persistent pain as a continual disruption of a person's ongoing life, involving the individual's sense of self or even causing a loss of self (Charmaz, 1983, Woodward et al., 1995, Eccleston et al., 1997, Honkasalo, 2000, Åsbring, 2001, Lillrank, 2003, Werner et al., 2004). Hellström (2001) described one of the factors as "*Maintaining the consistency of self*", explaining how their patients with persistent pain struggled to keep familiar characteristics of their selves alive, in order to preserve a coherent identity in their new life situation. A critical feature about whether or not persistent pain impacts on a person's identity is the extent to which aspects of the self are enmeshed with the experience of pain. Enmeshment refers to the extent to which aspects of the self are contingent on the presence or absence of pain (Morley and Eccleston, 2004). The notion of enmeshment is similar to the notions of entrapment described phenomenologically in qualitative studies of patients with pain (Kugelman, 1999, Hellström, 2001, Pincus and Morley, 2001). The close connection between a physiological trauma and the loss of self has previously been addressed in the following statement "*When a person discovers he or she will not be able to walk again, this is more than a physiological fact. In phenomenological terms, that person's very sense of identity is assaulted*" (Shepard et al., 1993). It is considered a threat to a person's sense of whom they are that generates a range of emotional responses, including fear and anxiety.

The experience of fear ran through all the interviews. One interesting finding was that all the informants except those in Typology III experienced fear of movement. The fear was not, however, described as a fear of moving

as such, but rather as what the consequences of the movement could be in the future. Markus and Nurius (1986) introduced the concept of possible selves as representations of individuals' ideas about what they might become in the future. Possible selves encompass a person's hopes, fears, goals, and threats that give meaning to a person and provide direction and motivation for behavior (Morley and Eccleston, 2004). The informants in typology III mentioned fear, but not in association with movement. Instead, fear seemed to be more associated to a specific situation such as undergoing a surgical procedure. The experience of fear and the related emotion of anxiety are considered, according to DSM-IV, to be universal and familiar to everyone (Tasman and First, 2004). The meaning of fear, however is not universal, as was shown in this study. There is rarely one object of fear in pain. More often there are potential fears that arise from the capacity of pain to threaten the whole range of a person's existence (Morley and Eccleston, 2004).

Honkasalo (2000) conceptualized chronic pain as an emotion, an *e-movere* described as an intense passionate movement, an intentional relation with a bodily posture taken towards the world. The neurologist Damasio (1994) emphasized the connection between emotions and the body by describing the essence of a feeling as "*the direct perception of a specific landscape: that of the body*". The role emotions play in the perception and experience of pain is considered to be important, though admittedly not well understood. By combining the gate control theory with Selye's theory of stress Ronald Melzack introduced a new model called the *body self neuromatrix theory* (Melzack, 1999). The body self neuromatrix theory included parallel somatosensory, limbic and thalamocortical components that subserve sensory-discriminative, affective-motivational and evaluative-cognitive dimensions of pain experience. The neuromatrix is to some extent genetically determined, but is modified by sensory influences and learning. The output pattern is called the "neurosignature". Another important feature of the neuromatrix theory is that the patterns of the nerve impulses are hypothesized to be triggered either by sensory inputs or centrally independent of any peripheral stimulation. The neuromatrix theory is important since it integrates new findings from brain-imaging studies, studies of the effects on stress on pain, and research on cognitive-behavioral factors and pain.

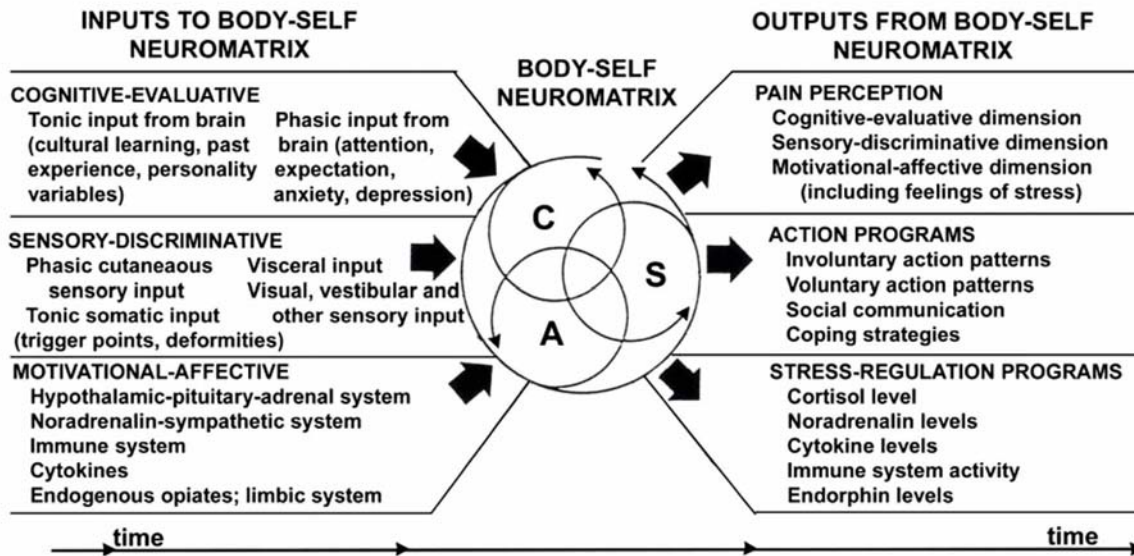


Figure 11. The body self neuromatrix theory. Melzack R. Published in *Pain Supplement* 1999: S121-S126.

The model represents yet another step in the evolution of more complex psychological models of pain. With this model Melzack hypothesizes that prolonged stress and ongoing efforts to restore homeostasis can suppress the immune system and activate the limbic system. The limbic system plays a central role in emotion (LeDoux, 1996), motivation and cognitive processes. There is, however, criticism of the ideas that the limbic system constitutes the emotional brain (LeDoux, 1996). The neuromatrix theory guides us away from the Cartesian concept of pain as a sensation produced by injury, inflammation or tissue pathology, and leads us towards the concept of pain as a multidimensional experience produced by multiple influences. What this model clearly describes is the close relationship between emotions, pain and movement. Future studies from a phenomenological perspective can further clarify the meaning of “*fear of moving*” while in pain.

Experiences of medical encounters were addressed by several of the informants. The informants in typologies I and II talked about negative experiences of medical encounters and the negative impact these had on their well-being and their rehabilitation processes. One negative experience was the long waiting period until they got help; another was the feeling of being ignored by the doctor, and a third the lack of understanding what it is like to live with pain. Therapy seeking is always preceded by some kind of problem and interpretation of experiences. What patients seek is a kind of confirmation and validation of their experiences (Toombs, 1987). The results of our study support the contention that traditional biomedicine has expert knowledge of

the objectified body, but little knowledge of the lived body (Bullington, 1999). Patients in other studies described how they were met with skepticism, lack of comprehension, rejection, ignorance and belittling (Johansson et al., 1996, Raymond and Brown, 2000, Östlund et al., 2001, Åsbring and Närvänen, 2002, Werner and Malterud, 2003). The informants in the present typology III described the positive impact a good medical encountering had on the rehabilitation process. Positive encounters with the health care profession boosted confidence, and gave the informants a sense of being believed in and being able to have a dialogue.

Many healthcare providers believe that their field is founded on scientific knowledge (Sassower and Grodin, 1987, Malterud, 2001) where knowledge is defined as facts that can be empirically verified using a biomedical model. Controlled experiments the sole basis on which clinical decisions are made and even apparently clear-cut medical tasks are not always as scientifically proven as we would like to believe. For example, issues like inter-observer variation when reading images (Koran, 1975, 1975, Sassower and Grodin, 1987, Elmore et al., 1994), manipulation and interpretation problems when interpreting laboratory findings (1991) and the doctor's personal experiences all affect diagnosis (Malterud, 2001).

The difficulty for medicine as a discipline is not the subjectivity, but that medical traditions lack strategies for the study of interpretive action, its dynamics and its consequences (Malterud, 2001). Leder (1990) suggests that medicine is flawed because of a refusal to accept that results are outcomes of interpretation. Clinical interaction requires the understanding of particulars to be integrated with the understanding of universals (Malterud, 2001). A patient's life, history and feelings are not easily translated into biomedical variables and statistics (McWhinney, 1989, Hunter, 1991, Malterud, 2001). Therefore, specific methods need to be designed to grasp the cultural gaps that sometimes distort diagnostic clarity (Gardner and Chapple, 1999, Malterud, 2001) and symptoms as experienced by the patient (Söderlund et al., 2000). Numbers alone can never provide the whole range of evidence needed for clinical work. Qualitative research can help bridge the gaps between theory and practice in medicine. This research could, for instance, provide a knowledge base for all kinds of health care professionals.

24. General methodological considerations

For the purpose of this thesis I chose the conceptual definition of Kori et al. (1990) for various reasons. Firstly, I was interested in using the TSK. I therefore wanted to use the conceptual definition linked to this specific

instrument. Secondly, “Fear of movement” does not address the exaggerated component of fear which I think is of significance. Most people are afraid of moving an affected body part, which is a quite normal reaction in an acute setting. I wanted to stress that I was interested in those patients who would need special attention for their cognitions regarding fear. Thirdly, pain-related fear is a broader term than fear of movement and kinesiophobia, that not only incorporates the specific fear of movement, but all kinds of fear related to pain.

During the time it has taken to write this thesis, knowledge regarding kinesiophobia has developed. How the concepts have been applied in the various articles reflects the knowledge base of that specific time. In Study I used kinesiophobia and fear of movement synonymously as defined by Vlaeyen et al. (1995). In Study II kinesiophobia was used more strictly. In Study III the term pain-related fear was used as an introductory term reflecting the state of the art. Pain-related fear is considered to be a more comprehensive construct since it has been proven that more than one specific fear contributes to the avoidance behaviour (Vlaeyen and Linton, 2000).

One might argue that this is all simply a matter of words. That was my opinion for a long time, I have now changed my mind. If one uses too many constructs (or conceptual definitions) for the same thing it will cause confusion in the application. When reviewing the use of kinesiophobia the construct was described with nine different names. It might be that there are small differences in conceptual understanding, but the message will not be clear. I think that this is the case with the three constructs ”pain-related fear”, ”fear of movement” and ”kinesiophobia”. These three constructs are used synonymously, although per definition they are not. As mentioned before these are all constructs put together by researchers.

There is an ongoing debate as to whether kinesiophobia is really a phobia or a fear. Kori et al. (1990) spoke mainly of kinesiophobia but did also write of “fear of painful reinjury”. In order to clarify the psychological difference Vlaeyen et al. (2002) compared the main features of specific phobia and pain-related fear in chronic pain according to the Diagnostic and Statistical Manual of Mental Disorders-IV (DSM-IV) (Tasman and First, 2004) and, in line with Kori’s original theory, found many similarities. One point at which they differ is that people with a phobia are aware that the fear is excessive and irrational, while most patients with pain reporting pain-related fear are convinced that their avoidance fills a protective function and is in no way excessive. In clinical terms this is of importance when it comes to knowing how to treat these patients. From a psychological point of view a phobia is treated

differently from a fear. The psychologist would need to know how to label the condition. From the orthopaedic surgeon's perspective and the physical therapist's perspective we would have to know if it is a condition we could treat or if we should refer the patient to a psychologist for a more extended investigation.

In research it is confusing to use the concepts as synonyms when building the theoretical framework. In my opinion it is not correct to use TSK to evaluate pain-related fear since TSK was constructed to measure kinesiophobia. For example, if I say that I am measuring pain-related fear with TSK, in order to investigate the association to pain intensity (measured by VAS). I then find an association between TSK and VAS. What will my interpretation be? Is pain-related fear associated with pain intensity or is it kinesiophobia that is related to pain intensity?

This reasoning becomes even more complicated when interpreting the results from the factor analyses performed on the Tampa Scale for Kinesiophobia. In a review, we found eight different names for ten factor models of the TSK ((Miller et al., 1991, Vlaeyen et al., 1995, Clark et al., 1996, Cohen et al., 2003, Gironde et al., 2003, Swinkels-Meewisse et al., 2003, Goubert et al., 2004, Lundberg et al., 2004, Burwinkle et al., 2005, Woby et al., 2005). The construct under investigation had nine different names. One might argue that these differences are simply semantic, but I would argue otherwise. It is obvious that this circumstance makes comparisons across studies difficult.

Most of the research related to kinesiophobia is based on various fear-avoidance models. There are arguments formulated against the fear-avoidance theory. Per definition fear is not related to avoidance. Most often avoidance takes place without the presence of fear (Goubert et al., 2004) Fear is a present-orientated state that is designed to protect the individual from a perceived immediate threat. It is usually directed toward a concrete stimulus, activity, or situation. Presumably, under the amygdalar control system (Gray and McNaughton, 2000), fear is the emotional manifestation of the fight or flight response (Cannon, 1929). Anxiety, on the other hand, is a future-orientated cognitive-affective state that appears to arise from the septo-hippocampal system (Gray and McNaughton, 2000). Others emphasise the fact that there is no detailed, experimental research about the precise and dynamic processes underlying the interrelationships between pain-related fear and avoidance (Goubert et al., 2004). Fear motivates defensive behaviour such as escape and anxiety-motivated preventative behaviour such as avoidance. By definition then one does not avoid encountering a threat that is

already present and one does not escape from something that is not yet present (Asmundson et al., 2004). Based upon this formulation an updated model called the fear-anxiety-avoidance model of chronic pain has been presented (Asmundson et al., 2004).

Fear-theory is frequently called two-process or two-factor theory (Mowrer, 1947). The observed lack of parallelism between fear and avoidance performance is probably the most frequently cited criticism of fear-theory (McAllister and McAllister, 1991). Although behavioural analyses have shown how previously neutral stimuli can acquire the ability to produce fear and channel learned behaviour appropriate to a threatening situation, a strictly behavioural analysis will never yield a fundamental (reductionistic) explanation of fear. That must come from an understanding of the underlying brain processes. Perhaps the earliest systematically gathered evidence supporting the existence and evolution of brain emotive circuits was provided by Darwin (1872) in *The Expression of the Emotions in Man and Animals*. In that contribution, Darwin pieced together observations on species ranging from dogs and cats to chimpanzees and humans, and concluded that each species displayed stereotyped behavioural patterns which had evolved to communicate the emotional state of the animal (McAllister and McAllister, 1991). There is now sufficient indirect evidence from neuropharmacological, brain lesion and brain stimulation studies to indicate the existence of a basic fear circuit. Fear is the central state that arises from the activity of a specific transiencephalic emotional circuit recruited when body safety is threatened.

To understand the assessment of fear of pain it is essential to identify conceptual and definitional issues about distinctions between fear and anxiety. The constructs fear and anxiety are historically overlapping and most often used interchangeably. Nevertheless, various theoretical models, as well as conceptual and empirical work have emphasized that these constructs differ (McNeil et al., 1993, Craske, 1997, Barlow, 2002). The meaning of pain in relation to emotion is also a critical issue (McNeil and Wovles, 2004). In many cases of pain, fear may both be expected and typical. To not experience at least some degree of fear about pain may be a kind of denial.

Although no model can be considered perfect, I would argue the simpler the better. The above-mentioned models are, in my opinion for research purposes only. Our intention must be to bring these models alive in a clinical situation. This, I would argue, was the best thing about the original model of Vlaeyen et al. (1995): it could easily be applied and understood in a clinical setting. I consider this a pedagogical challenge for future research. I would further argue for more focus on the patient perspective. None of the present

fear-avoidance models have been derived from, or even supplemented with, the patient perspective. In Figure 12 a hypothetical model of fear of pain-related movement model has been supplemented with the health care providers' impact on the patient and with a stronger focus on the meaning of movement.

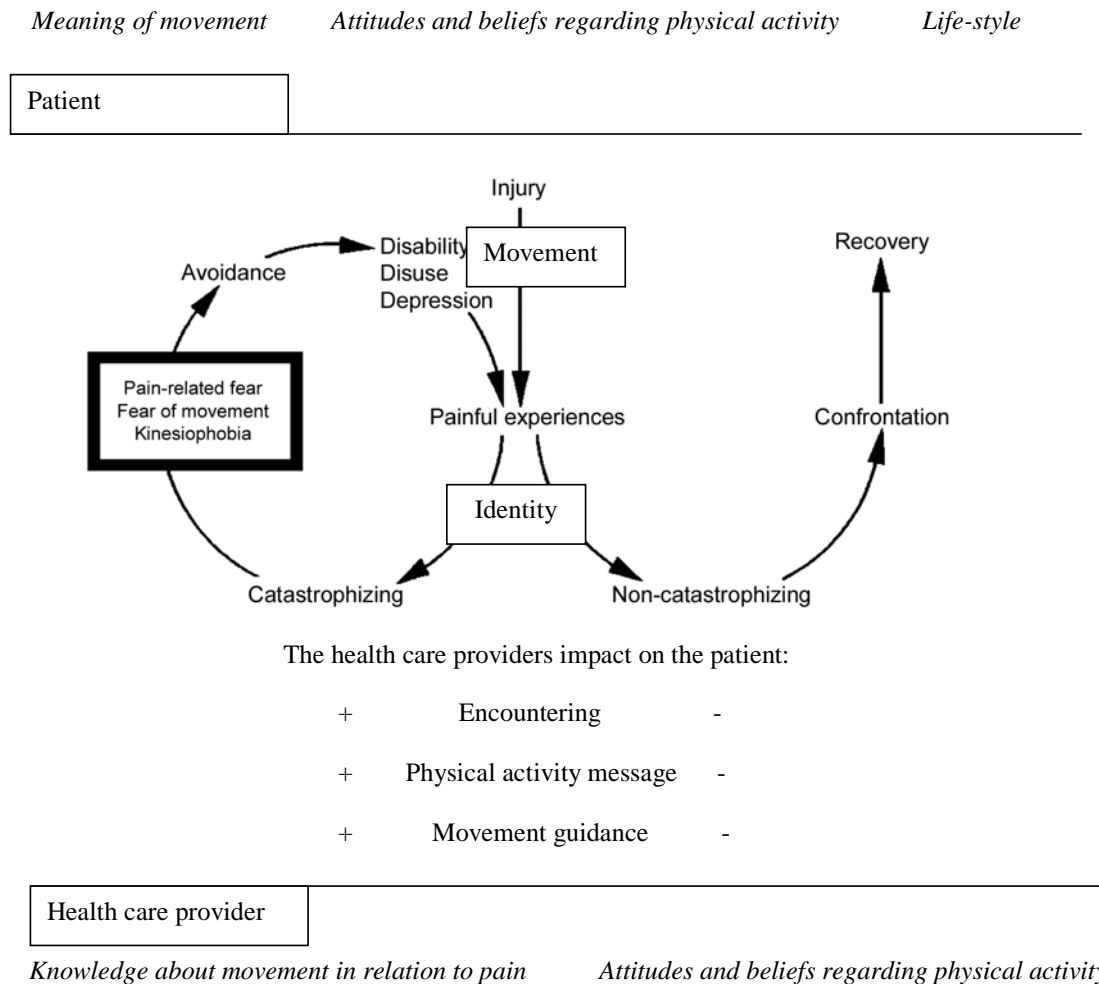


Figure 12. A hypothetical model of fear of pain-related movement based upon the results of this thesis. This model is based on the original model by Vlaeyen et al. (1995).

The basis of this thesis was the belief that pain can be apprehended and studied as a concept, without needing to pinpoint the actual cause. This was partly based on clinical experience and partly on previous research (Bergman, 2002, Gerdle et al., 2004). The majority of the patients (59%) in this thesis reported pain from the lumbar region. Only a small proportion of cases of back pain (approximately 10%) can be attributed to an underlying cause (Croft and Raspe, 1995). This is not to say that a thorough examination is not warranted. However, it should also include a thorough examination of the

patient's pain. This examination should be performed from the perspective that pain is a complex perceptual experience that involves sensory-discriminative, affective-motivational and cognitive-evaluative components (Melzack and Wall, 1965, Melzack and Casey, 1968). These components can be found in all types of pain regardless of the origin of pain. So regardless of whether the pain comes from a fractured leg, a sore back or an overused arm, it must be taken into account. Pathological or physiological evidence of tissue damage is not required for a diagnosis of pain to be made.

Including some subjects actually means excluding other possible subjects who might have contributed to the results in an interesting way. There is always a risk for exclusion bias. Patients with a confirmed neurological or rheumatic disease were excluded. It is important to add that we did hence not include patients with fibromyalgia since we consider that diagnose as rheumatic disease according to the American College of Rheumatology criteria (Wolfe et al., 1990). Fibromyalgia or FMS and persistent pain are often considered to be the same condition in both clinical and research setting. In some of the research regarding TSK patients with persistent pain are compared to fibromyalgia patients (Goubert et al., 2004, Roelofs et al., 2004, Burwinkle et al., 2005, Woby et al., 2005).

Subjects who did not possess an adequate understanding of the Swedish language were excluded. In Studies I and II it was interesting to note that more of the non-responders were immigrants. The importance of testing a questionnaire on several populations has been emphasized (Bergström et al., 1998). There is, however, no discussion about how to deal with the subpopulations that do not consider the validated language their native language. Swedish society includes a large number of immigrants and it must be assumed that they are also subject to pain. By excluding people on the basis of language important findings may have been lost. This question is of interest in terms of the generalisability of the findings of a psychometric evaluation. However, Lindström et al. (2003) found that immigrants reported poorer levels of health, more pain, pain-behaviour, disability, distress and poorer physical performance when entering an outpatient-based multidisciplinary, behavioural and cognitive rehabilitation programme. We must therefore find ways to include immigrants in our screening procedures.

In my point of view the choice of inclusion and exclusion criteria are very central to how we will be able to generalise from our results to a clinical setting. The results of Study I indicate that TSK-SV was a relevant and reliable questionnaire for use on a Swedish population of patients suffering from persistent low back pain. Even so, I used the questionnaire in

populations with heterogeneous musculoskeletal pain (Studies III). Could that be considered correct? My reason was that I consider persistent pain as one concept in relation to kinesiophobia. In Study III even some acute patients were included. It turned out that they did not differ from the patients with persistent pain when it came to the subjective estimation of kinesiophobia. One possible explanation might be that those patients suffered from recurrent pain.

Missing values were treated differently in the various studies. In Study I all questionnaires with missing values were excluded (n=16). In this thesis those 16 questionnaires were included. We chose not to replace the missing values (neither by the mean value nor by the median value), since we did not consider it correct to do so.

Since TSK is constructed as a sum score all items need to be filled out to be able to sum a total score. None of the studies, regarding the development and evaluation of TSK, addresses how they treat missing values. The issue of missing values is an issue more related to research than to a clinical setting. Since we mailed out the questionnaires the patients were not able to ask questions. A few called to clarify the meaning of some items, but we can not be sure of why those who do not filled out some items did not do so.

Phenomenological sampling is essentially purposive, meaning that the informants must fulfill at least one criterion with regard to their experience of the phenomenon of interest (Colaizzi, 1978, Polkinghorne, 1989, Presnell, 2004). Rice and Ezzy (1999) identified 12 sampling strategies for use in qualitative research, including phenomenology. Randomisation, and a requirement of representativeness of sample demographics are not features of these approaches (Rice and Ezzy, 1999). Participants also need to be fluent in the language of investigation, and to possess the necessary cognitive skills to enable reflective contemplation of the phenomenon under investigation (Colaizzi, 1978, Polkinghorne, 1989, Presnell, 2004). Each of these requirements contributes to influencing the analysis and interpretation of data, as well as to any generalizations drawn from it.

A question with no clear answer is how many informants constitute an adequate sample size to faithfully explore the phenomenon under investigation. When contrasted with quantitative studies, sample sizes in phenomenological investigations may appear to be small (Patton, 1987, Holloway, 1997, Smith, 2003, Presnell, 2004). By contrast, phenomenological studies produce voluminous data. There are both practical limits as to how many pages of data can be analysed, as well as to the researcher's ability to

maintain a strong and oriented relationship to the phenomenon (Presnell, 2004).

Although there are many similarities between qualitative and quantitative research methods some of the procedures are very different, because of the different nature and assumptions of the data and questions to be answered. The effect of an investigator on a study, the principles and consequences of sampling and the process of organization and interpretation during analyses all affect research and are closely related to different aspects of validity. Malterud (2001) mentions reflexivity, transferability and interpretation and analysis as factors that affect results. In other words, reflexivity is about the researcher's preconceptions, transferability is about sampling procedure and interpretation and analysis are self-evident. To address validity in qualitative studies Malterud suggests that the researcher's preconceptions are explained and presented. Purposeful and theoretical sampling are done to obtain qualitative material. These sampling procedures should be based on a theoretical framework. A thorough well prepared and well documented analysis is what distinguishes a scientific approach from superficial conjecture.

25. Ethical considerations

The response rate was low in some of the subgroups. The reasons for this were mainly that our desire to conform to the ethical principles of "The World Medical Association Declaration of Helsinki Ethical Principles for Medical Research Involving Human Subjects" (Rickham, 1964) restricted the scope of our research and led to low response rates. To safeguard the patient's interest in terms of personal integrity we respected the privacy of the subject and the confidentiality of patient information. We therefore only sent out a reminder in Study I. Furthermore, in order to minimize the impact on the patient's physical and mental integrity we distributed the questionnaires by mail.

Another reason for mailing the questionnaires was that since the construct under investigation was "fear", we considered it inappropriate to distribute the questionnaire before or after the scheduled appointment with the orthopedic surgeon, as most of the patients had waited years for their appointment. We expected their anxiety levels to be high on those occasions. This was supported by the findings of others (Colombotos, 1969, Cook et al., 1993). However, Frennered et al. (2004) showed that the patients rated less anxiety in the hospital setting than at home.

Furthermore, to minimize the impact on the patient's physical and mental integrity we distributed the questionnaires by mail. Finally, we did not want

the data to be affected by personal relationships. The patients in Study III came from small town communities where it is common to be on familiar terms with the physiotherapist. We found that a response rate of 89%-92% (Subgroup B + F) when the patient were supposed to return the questionnaire in combination with a visit to their treating orthopaedic surgeon, as compared to 38% (subgroup G) when they should mail in a response to someone with whom they did not have a connection.

Although, all studies are performed within the ethical principles of the Helsinki Declaration, they are interpreted in different ways. It is interesting to note, however, that very few studies address the issue of the ethical questions related to the response rate. In research related to kinesiophobia only Swinkels-Mewisse et al. (2003) mentioned difficulties in the study design that might have affected their results. Testa (1993) suggests that questionnaires should not be sent home to patients due to the lower response rate.

26. General limitations

The main limitations of this thesis are in the study design. The study design sets the limits for interpretation and generalisation of the results. Since this thesis is of a descriptive design there are certain limits as to what conclusions can be drawn. I prefer to speak of occurrence instead of prevalence. An epidemiological design could have told us with greater security about the prevalence of kinesiophobia. This is not to say that we could not use the results of this thesis, but that a certain amount of caution must be used when interpreting the data. This also goes for interpreting the results of the regression analysis. Since it was a cross-sectional study it would be wrong to talk about risk, in which the data should stem from a longitudinal study design.

All measurements were based on self-reporting. For both constructs (fear and pain) there is an (over)reliance on self-reports (McNeil and Wovles, 2004). Verbal reports as well as the other methods (observation by others and instrument/apparatus) have limitations (McNeil and Wovles, 2004). The best methods of assessment are multimodal and multi-method. Such an analysis is, however, not always possible in the clinical setting. Once again, we need to be cautious when interpreting the results.

The criticism of qualitative methods has concerned mainly two issues: its dependence on the research subject, and its questioned ability to allow generalizations (Hellström, 1998). Criteria for evaluating the adequacy of an interpretive account often mentioned are consistency (Karlsson, 1993, Leonard, 1994, Hellström, 1998) and plausibility (Leonard, 1994, Hellström,

1998). Qualitative researchers hold different views on the issues of generalization. Some discard all attempts to generalize, but hold an antitheoretical and antigeneralizing position (Schwandt, 1997). Others take a less radical approach and argue that generalizations could be made, for instance, by analytic generalization, meaning that researcher uses findings from a specific case to test, refining, or modifying some theory, concept or model (Yin, 2003).

27. The gender perspective

In the present thesis there was a statistical significant difference between men and women in relation to self-reported kinesiophobia. These results are interesting in relation to what is known about the prevalence of musculoskeletal pain. Musculoskeletal symptoms are more common among women than men (Bergman et al., 2001, Gerdle et al., 2004, Thomas et al., 2004), and women's pain is classified as medically unexplained more often than men's (Sharpe et al., 1994, Speckens et al., 1996, Werner and Malterud, 2003). Usually, more women than men report high levels of anxiety (Craske, 2003). Due to the design of this study our results must be interpreted with caution. Even so, it is interesting to speculate what the difference could be attributed to. Are men more prone to tell the truth about fear in relation to movement as opposed to anxiety in general? Are they actually experiencing a higher degree of pain-related fear? These are questions to be answered in other studies with other types of study design.

We did not analyse our interviews on the basis of a particular feminist theory, such as described by Werner and Malterud (2003). It is interesting to note that all the informants in Typology III were women. I am curious about to know about why that is. Do women in general more easily accept things and find ways out, as described in Typology III? Werner et al. (2003) and Steihaug et al. (2002) have explored women's experiences of rehabilitation programs and come to the conclusion that women benefit more from rehabilitation programs designed to meet their particular needs.

28. Clinical implications

On the basis of our studies, TSK-SV can be considered reliable and to have enough evidence of its validity to be used on a Swedish pain population. I can therefore recommend use of the TSK-SV in clinical situations in order to obtain a rough indication of that person's level of pain-related fear beliefs in relation to movement. Screening would enhance the allocation of resources to those patients who are most likely to benefit from them. Screening for

kinesiophobia is of relevance for the design of a successful rehabilitation program. Using simple questionnaires such as the TSK is one way of identifying patients with pain with elevated scores of kinesiophobia.

In this study we also found a high occurrence of kinesiophobia among patients with persistent musculoskeletal pain. The primary health care setting has been considered one of the most important arenas for early identification of disability (Buer, 2003, Enthoven et al., 2003). Primary health care is often poorly equipped to assess psychological variables (Linton and Boersma, 2003). I would argue that this is also the case for an orthopaedic health care unit. We must change the perspective and think that it is not where we meet the patient that matters, but who the patient is.

Fear is a normal psychological reaction. Fear of movement is also a normal psychological reaction. Kinesiophobia is not a disease but a reaction to a threat. To have an understanding for normal psychological reactions is of great importance when working with people. Not only should we screen for fear, we should also acknowledge what it means to that person, not being able to move as before. Medicine has been slow to realize that how people feel about their medical condition is a major factor in the outcome of treatment. In the same way, psychologists lack knowledge about the body and movement. The psychology of pain is a field, to which we in orthopaedic research should pay more attention. Not only should we be aware that the patients are afraid, we should also take steps to reduce or prevent the fear and to encourage movement.

What are the clinical implications of these findings? A rehabilitation program is about setting goals and achieving them. Our results indicate that patients might be suffering from a deep existential crisis and living in chaos, unable to plan for the future or work towards a goal. Goals, whether implicit or explicit, contribute to a person's identity (Morley and Eccleston, 2004). It is evident that all informants experienced a dramatic change of their identity. If the patients are not able to imagine a future, they will most likely be unable to set up and achieve a goal. The goal for medicine, according to Svenaeus (2000) is to bring the patient back to homelikeness, that is to health. The challenge for today's health care is to find the means to guide each patient back home, to where they feel at home in their changed bodies.

Movement is essential to health and is considered both a means and a goal in physiotherapy. Physical therapists have a unique position in the health care system, since we focus on achieving health through movement. By helping patients to move and confronting them with their fear of movement we also touch on their feelings and their self images. We need to extend our

knowledge about what it means to the patient in an existential context to not be able to move as before. From a clinical perspective it is also important to stress that the informants in this study were orthopaedic patients.

Qualitative studies have to date focused mainly on patients with fibromyalgia or chronic fatigue syndrome. To be affected by pain is a normal psychological reaction. It must therefore be considered normal to take all these psychological and existential factors into account when encounter the patients. Regardless of the diagnosis and the medical setting, a patient will be affected by experiencing pain. This is not to say that biomedical examination is not of importance, however it should be complemented by a perspective that takes the lived body into account.

29. Future implications

Several questions have arisen during this study process and should lead to future studies.

- There is still a lack of a conceptual definition of debilitating fear of movement in relation to pain. A consensus should be made.
- The domain of kinesiophobia, pain-related fear and fear of movement needs to be further specified.
- The science of movement needs to be incorporated in to the fear-avoidance models. Physical therapists need to take part in developing such a theoretical framework.
- There is still a lack of an operational definition of debilitating fear of movement in relation to pain. Based upon a specified conceptual definition a clear operational definition should be made.
- What association is there between fear of musculoskeletal pain and the various components of movement?
- There is evidence of a high prevalence of kinesiophobia among patients in orthopaedic care, but what can be done to reduce the fear?
- In what way do health-care providers' attitudes and beliefs regarding physical activity in relation to musculoskeletal pain influence the patient's attitudes and beliefs?
- There is a lack of the patient perspective in relation to kinesiophobia. Further studies needs to explore how the patient experiences to move with pain.

CONCLUSIONS

I. The Swedish language version of the Tampa Scale for Kinesiophobia (TSK-SV) questionnaire was found to be reliable and evidence supported its validity, although the results indicated a lack of construct validity.

II. The TSK-SV is a multidimensional questionnaire, which measures different conceptual aspects related to the phobic components of fear and avoidance.

III. Kinesiophobia is a commonly seen factor in patients with musculoskeletal pain.

IV. Kinesiophobia is associated with pain variables (pain severity and pain intensity), physical exercise measures (disability) and psychological characteristics (interference, life control, affective distress, solicitous response and depressed mood).

V. The experience of moving with pain implies much more than the pure physical movement. Life with pain was a threatening challenge to the informants' existence and identity.

An exaggerated fear of movement (kinesiophobia) was frequently reported by patients who sought care for persistent musculoskeletal pain (Study I-III). Fear of movement is closely linked to avoidance behaviour. Since avoiding movement is negative for the individual in many ways, movement and physical activity must be encouraged. This thesis showed that moving with pain has a deep existential impact on the individual (Study IV). Thus how movement is encouraged must be related to the meaning each individual subscribes to movement. Movement is essential to life and joy and must be incorporated in rehabilitation of patients with pain to a greater extent. The challenge for the health care system is to provide a system that reduces fear and encourages movement.

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APPENDIX

Tampascale for Kinesiophobia (TSK)

(original version Miller RP, Kori SH, Todd DP, 1991)

1. I am afraid that I might injure myself if I exercise.	1	2	3	4
2. If I were to try to overcome it, my pain would increase.	1	2	3	4
3. My body is telling me I have something dangerously wrong.	1	2	3	4
4. My pain would probably be relieved if I were to exercise.	1	2	3	4
5. People are not taken my medical condition seriously enough.	1	2	3	4
6. My accident has put my body at risk for the rest of my life.	1	2	3	4
7. Pain always means I have injured my body.	1	2	3	4
8. Just because something aggravates my pain does not mean it is dangerous.	1	2	3	4
9. I am afraid that I might injure myself accidentally.	1	2	3	4
10. Simply being careful that I do not make any unnecessary movements is the safest thing I can do to prevent my pain from worsening.	1	2	3	4
11. I would not have this much pain if there were not something potentially dangerous going on in my body.	1	2	3	4
12. Although my condition is painful, I would be better off if I were physically active.	1	2	3	4
13. Pain lets me know when to stop exercising so that I don not injure myself.	1	2	3	4
14. It is really not safe for a person in my condition to be physically active.	1	2	3	4
15. I can not do all the things normal person do because it is too easy for me to get injured.	1	2	3	4

- | | | | | |
|--|---|---|---|---|
| 16. Even though something is causing me a lot of pain, I don't think it is actually dangerous. | 1 | 2 | 3 | 4 |
| 17. No one should have to exercise when she/he is in pain. | 1 | 2 | 3 | 4 |

Tampaskalan för kinesiofobi –svensk version (TSK-SV)
(Lundberg, Carlsson och Styf, 2004)

Nedan följer olika erfarenheter som andra patienter delgivit oss. Var vänlig och ringa in lämplig siffra från 1-4 för varje påstående. Läs varje påstående och besvara varje påstående så gott Du kan.

	Håller inte alls med		Håller med helt	
1. Jag är rädd för att jag kan skada mig själv om jag tränar.	1	2	3	4
2. Om jag försökte träna så skulle min smärta öka.	1	2	3	4
3. Min kropp säger mig att jag har någon allvarlig åkomma.	1	2	3	4
4. Min smärta skulle troligen lindras om jag motionerade.	1	2	3	4
5. Människor tar inte mitt medicinska tillstånd tillräckligt allvarligt.	1	2	3	4
6. Min skada har försvagat mig kroppsligen för resten av mitt liv.	1	2	3	4
7. Smärta beror alltid på kroppslig skada.	1	2	3	4
8. Bara för att någonting förvärrar min smärta behöver det inte betyda att det är farligt.	1	2	3	4
9. Jag är rädd för att jag skulle kunna skada mig själv oavsiktligt om jag tränade.	1	2	3	4
10. Att vara försiktig med onödiga rörelser är det bästa jag kan göra för att förhindra att smärtan förvärras.	1	2	3	4
11. Jag skulle inte ha så här ont om det inte var något farligt på gång i min kropp.	1	2	3	4
12. Även om det gör ont klarar jag mig bättre om jag är fysiskt aktiv.	1	2	3	4
13. Smärtan säger mig när jag skall sluta träna, så att jag inte skadar mig själv.	1	2	3	4

14. Det är verkligen inte ofarligt för en person i mitt tillstånd att vara fysiskt aktiv.	1	2	3	4
15. Jag kan inte göra samma saker som andra eftersom det är för stor risk att bli skadad.	1	2	3	4
16. Även om någonting orsakar mig mycket smärta så tror jag faktiskt inte att det är farligt.	1	2	3	4
17. Ingen ska behöva träna när hon eller han har ont.	1	2	3	4